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The lived experience of vulnerability among adults ageing with deafblindness an interpretative phenomenological analysis

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The Lived Experience of Vulnerability among Adults Ageing with Deafblindness: an Interpretative Phenomenological Analysis

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Thesis submitted in fulfillment of the requirements for the
degree of Doctor of Philosophy

2020

ABSTRACT

Deafblindness is a complex impairment and there is a paucity of qualitative research into the lived experiences of deafblind people. Little is also known about the lived experience of vulnerability, yet deafblind people are often presented as one of society's most vulnerable groups. The research presented in this thesis is the first known UK based study of the lived experience of vulnerability among older people ageing with deafblindness. It therefore makes an important contribution to the limited body of knowledge about these phenomena and helps to give voice to a group often excluded in the gerontological and deafblind literature. The research was completed in two stages: first, a systematically conducted review and second, a qualitative study adopting interpretative phenomenological analysis as the research approach. Data were collected via eighteen semi-structured interviews, with eight participants aged 49-83. Two participants have congenital rubella syndrome and six have Usher syndrome. A detailed account of the methods used is provided, offering guidance to other researchers regarding the inclusion of deafblind people in qualitative study.

Problematising the notion of deafblind people as permanently and immutability vulnerable, participants interpret their vulnerability as layered: vulnerable about, vulnerable to and vulnerable when. Although interrelated, the latter layer is predominant: vulnerability is experienced as time-limited, and situation and setting specific, reflecting Mackenzie and colleagues' (2014) taxonomy. The experience of being misunderstood or perceived as incapable is observed as a shared experience of situational vulnerability and adversely affects participants' lives, negating their own coping strategies and the effectiveness of available support.

Participants' experiences highlight the inadequacy of the long-standing congenital-acquired divide in deafblind research, policy and practice. Deafblindness, a non-stable impairment, is more an experience than an identity; central to this experience is difficulty compensating. This transcends the inability of one sense to compensate for impairment in the other and is multi-faceted.

Although participants experience vulnerability, ongoing difficulties, change and consequent adaptation, they adopt various coping strategies, and demonstrate creativity as they develop solutions to the challenges they encounter. Though these vary, the ways in which participants manage their difficulties, and the attributes of the care and support they value, respond to the very elements they identify as generating their felt vulnerability. The thesis concludes by outlining the implications of these findings for policy, practice and future research.

ACKNOWLEDGEMENTS

I have been very fortunate to have had the support of so many people during the completion of this study. First, very many thanks to my excellent supervisors, Professor Jill Manthorpe and Professor Anthea Tinker. Thank you for your guidance, constructive feedback, and encouragement. Thank you for sharing your wisdom with me and for your kindness. I have learnt an enormous amount from you both.

Thank you to the eight participants, without whom there would be no study. Thank you for so generously sharing your experiences with me. You inspired me, you moved me, you made me laugh. It was a pleasure to meet you all.

I extend my thanks to Jay Morton-Thomas, Tracie Hunt and Tom Mould for their support as interpreters, which extended beyond the interviews and helped give voice to those so often excluded.

Thank you to Dr. Kritika Samsi and Dr. Ken McFadyen for your guidance on interpretative phenomenological analysis (IPA).

I am very grateful to those who provided financial support: the British Association of Social Workers and Staffordshire University.

Thank you to those working in the deafblind field, for supporting in several ways. Thanks to *Sense* and *Sensing Change* for assisting with recruitment. Huge thanks to Liz Duncan – who knew a meeting at midnight in a lift in a Romanian airport, would lead to ongoing collaboration? And to Walter Wittich – thank you for sharing so generously your wisdom and expertise, and for your encouragement. Thank you for being a wonderful writing partner and for e-mailing virtual hugs.

Thank you to the many colleagues and friends who have supported me: my fellow PhD students, Dr. Val D'Astous, Dr. Nicole Batsch, and Dr. Suzie Snowden, and colleagues at the Health & Social Care Workforce Research Unit, especially

Dr. Katharine Orellana – your words of encouragement were always timely and valued; Ian Lloyd, Dave Mason, Fern Basnett and David Collins. Particular thanks to Dr. Colin Watt for reading draft chapters and for reassuring and intellectually stimulating conversation about them. Thanks to Caroline Lee and David Childs for taking on extra work to give me space to study, and huge thanks to Jess Wagner – I hope I can help you as you start your doctoral studies, as much as you have supported me. Thank you to my friends John Elson and Sharon Gayle – if I ever need a social worker, I hope it will be someone like you.

A huge thank you to my parents. No matter what I choose to do, you always support me, encourage me and have faith in me. I would not have achieved what I have without you.

Finally, thank you to my wonderful husband Simone. For reading yet another paragraph or chapter, for listening to me talk endlessly about the study and helping me organise my thoughts, for keeping me supplied with tea and coffee, and for encouraging me throughout. With you, I can be vulnerable, but always feel safe.

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GLOSSARY

Access to Work

Access to Work (AtW) is a United Kingdom (UK) based publicly funded programme, through which grants are available to eligible disabled people, to support them to access or remain in paid employment. The money can be used to finance adjustments not made by employers under their Equality Act 2010 obligations. These include the provision of specialist equipment, support worker services or assistance getting to and from one's place of employment.

Activities of Daily Living (ADL)

Activities of daily living are those activities necessary to function independently. These include personal care tasks, such as washing, grooming, getting dressed, and using the toilet.

Block Alphabet

Block Alphabet is a tactile form of communication used by some deafblind people. It is considered easier to learn than other forms of tactile communication, and involves the 'speaker' using their index finger to spell out words in block capital letters on the palm of the 'listener'. The speaker should pause slightly at the end of each complete word.

Braille

Braille is tactile system of reading and writing used by some visually impaired and deafblind people. In makes use of a series of raised dots to represent letters of the alphabet, punctuation symbols and letter groupings. The reader feels the dots with their fingers, moving from left to right. Although originally used to provide permanent information on paper, braille is now used in digital communication. Some smartphones, computer keyboards, instant messaging software and social media platforms make use of braille displays or braille output devices.

British Sign Language (BSL)

British Sign Language (BSL) is the first or preferred language of the Deaf community in the UK. It was officially recognised as a language in its own right by the UK government on 18th March 2003. BSL does not rely solely on the hands to create meaning, but also the head, face and body. It has its own system of syntax and grammar, different to English, and its productive and established lexicon consist of five parts: hand shape, movement, location, orientation and non-manual features (facial expression and mouth and lip patterns).

Cases (in interpretative phenomenological analysis)

In interpretative phenomenological analysis, a case is the data, in the form of a written transcript, for each participant in the study.

Communicator-Guides

Communicator-guides are qualified support workers who 'act as the eyes and ears' of those with acquired deafblindness, enabling them to undertake instrumental activities of daily living. Since 2001, statutory guidance has required local authorities in England to make such one-to-one support available to those with an assessed eligible need.

Congenital Rubella Syndrome (CRS)

Congenital Rubella Syndrome (CRS) is infection of a foetus with the rubella virus (also known as German measles), subsequent to infection of the mother during pregnancy. Those infected may develop health problems and impairments, which vary in nature and extent dependent on the stage of pregnancy at which infection occurred. These problems may include deafness, cataracts, damage to the liver and spleen, heart problems and intellectual impairment. Although present at birth, some conditions manifest later in life, including diabetes and thyroid problems. Although once a main cause of congenital deafblindness, CRS is now rare in countries with vaccination programmes.

Deaf / deaf

The Deaf/deaf distinction was introduced by Woodward (1972), in order to demarcate different groups of people with different experience. Essentially, 'deaf' refers simply to the audiological condition of hearing loss, while 'Deaf' refers to those who belong to a shared language (sign language) and culture. When referring to both groups, the term d/Deaf may be used.

Deaf Relay Interpreter

A Deaf relay interpreter is a Deaf person, who works alongside a BSL/English interpreter, to support Deaf people with additional communication needs to access sign language and therefore communicate effectively. This may include work with Deaf people with learning disabilities or mental health problems. The relay interpreter adapts the sign language of the BSL/English interpreter to support the understanding of the Deaf person with additional needs.

Deafblind Manual

Deafblind manual is a tactile communication method used by some deafblind people. It is an adapted form of finger spelling, taken from British Sign Language. Each letter is spelled out onto the hand of the recipient.

Direct Payments

Direct payments are a cash payment made by local authorities to an eligible individual, in order to meet their social care needs. Payments are made in lieu of the local authority arranging or directly providing services. Direct payments are not means tested and the money can be spent on non-residential services, including community equipment and residential accommodation for a maximum period of four weeks within any 12-month period. In England, they are governed under sections 31-33 Care Act 2014 and the Care and Support (Direct Payment) Regulations 2014.

Electro-magnetic hypersensitivity

Electro-magnetic hypersensitivity (EHS) is a condition characterised by non-specific symptoms that include tiredness, nausea, concentration problems and dermatological symptoms. Those reporting to experience EHS attribute such symptoms to exposure to electromagnetic fields. Nevertheless, the condition has no scientific basis or recognised medical diagnosis.

Expressive communication

Expressive communication is the transmission of messages to another person in a way that makes sense

Health and Social Care Professions Council (HCPC)

The Health and Social Care Professions Council (HCPC) is a regulator of health and care professions in the UK. Between 2012 and 2019, the HCPC was the regulator of social workers in England.

Instrumental Activities of Daily Living (IADL)

Instrumental activities of daily living (IADL) are those tasks necessary for independent living, but not basic functioning. They are more complex than activities of daily living (ADL) and include managing finances, preparing meals, shopping, and making telephone calls.

Intervenors

Intervenors support deafblind people with any functional activity. They exist globally under different names, including partners, guide-helps and interpreter-guides. In the UK, intervenors ordinarily work with congenitally deafblind children and adults, while communicator-guides is the term used for those who support people with acquired deafblindness.

Lip Reading

Sometimes termed speechreading, lip reading is a method used by some deaf and deafblind people (with residual vision) to understand speech. It involves close observation of the movements of the speaker’s lips, mouth, face and tongue.

Long Cane

A long cane is a mobility aid used by some visually impaired and deafblind people. Following a period of training, the person uses the cane, rolling or tapping it from side to side as they walk, in order to navigate and avoid obstacles. Long canes are ordinarily white, in order to alert others that the user is visually impaired. In the UK, marking a white long cane with red stripes is an indicator to others that the person is deafblind.

Mobility Training

Mobility training can be provided to visually impaired and deafblind people in order to help them develop or relearn skills needed for independent and safe travel. The training may involve instruction on using mobility aids, such as long canes, how to plan routes, making use of public transport and safe road crossing.

Moon

Moon is a form of tactile reading, devised by William Moon in 1845. Letters of the alphabet are represented by 14 different raised characters. It is considered easier to learn than braille, but is less widely available.

National Register of Communication Professionals with Deaf People (NRCPD)

The National Register of Communication Professionals with Deaf People (NRCPD) is a voluntary regulator of communication and language professionals working with d/Deaf and deafblind people. The organisation hold registers of sign language interpreters, deafblind manual interpreters, note takers and speech to text reporters.

Personal Budgets

In England, according to section 26 Care Act 2014, a personal budget is a statement within an adult's care and support plan. This statement specifies the cost of the care and support to the local authority meeting the adult's needs, the amount the adult must pay towards that cost, and, if the local authority has to pay towards the cost, the amount it must pay. In policy and practice, a personal budget is a set overall budget, drawing on adult social care department monies only, which an adult can use to spend on services and support to meet his/her needs. The personal budget may be received as a direct (cash) payment, managed by the local authority or a combination of these. The budget can be spent on services from the local authority or other providers.

Receptive communication

Receptive communication is the process of receiving and understanding messages expressed by others.

Rehabilitation Officer for Visual Impairment (ROVI)

Rehabilitation Officers for Visual Impairment (ROVI) are trained and qualified human services professionals who provide specialist assessment, training and advice to visually impaired and deafblind people. They can assist individuals with communication, mobility and ADL/IADL, assess the need for and provide training on the use of specialist equipment, and offer emotional support.

Safeguarding Adults

'Safeguarding adults' involves a broad scope of policy and practice aimed at upholding an adult's right to be safe. This includes investigations following allegations or disclosure of abuse or neglect, and also preventative work and after-care. The Care and Support Statutory Guidance (Department of Health 2016:para.14.7) defines adult safeguarding as: 'Protecting an adult's right to live in safety, free from abuse and neglect. It is about people and organisations working together to prevent and stop both the risks and experience of abuse or neglect, while at the same time making sure that the adult's wellbeing is promoted.'

Snellen Chart

A Snellen chart is a tool used by ophthalmologists to assess and measure visual acuity. Ordinarily, they consist of 11 lines of capital letters. The number of letters increases in each line, while their size reduces.

Social Work England

Established by the Children and Social Work Act 2017, Social Work England is the regulator for social workers in England, taking over from the HCPC in December 2019.

Symbol Cane

A symbol cane is a mobility aid used by some visually impaired and deafblind people. It is a short cane, held in front of the person's body and its sole purpose is to alert others that the user is visually impaired (white cane) or deafblind (red and white striped cane).

Tactile British Sign Language

Tactile, or hands-on, British Sign Language is an adapted form of BSL used by some deafblind people. The recipient places their hands over those of the signer, in order to feel rather than see the signs made.

Usher syndrome

Usher syndrome is a genetic, autosomal recessive disorder and the most common cause of deafblindness acquired earlier in life. There are three types of the condition: type I and II are characterised by congenital profound deafness (Type I) or hearing impairment (Type II) and progressive sight loss owing to retinitis pigmentosa (RP), manifesting in childhood or early adulthood; type III is characterised by progressive hearing and sight loss (as a result of RP), with onset in adolescence.

'We can never know what it is like to be both deaf and blind unless we are. I believe it is both more awesome and less awesome than we imagine'

(Sauerburger, 1993:9)

INTRODUCTION

Lillrank (2012:282) observes that 'research questions often originate from personal interests and commitments that researchers care deeply about'. The topic of this thesis has undoubtedly emerged from both professional and personal interest. In 1997, while working in the North West of England, I took the opportunity to take British Sign Language classes at the local Adult Education College. During one of these classes, a representative from a local organisation for the visually impaired met with us to request volunteers for the deafblind social group that she facilitated. I was intrigued, and duly volunteered. The following week, for the first time in my life, I met a deafblind person, whom I shall call Barbara (not her real name). Barbara was profoundly Deaf and registered blind (now termed severely sight impaired (Dementia and Disabilities Unit 2017)). As I sat next to her, she felt my presence and extended out her hand to receive tactual communication. With my rudimentary deafblind communication skills, we muddled through a game of bingo and engaged in conversation. After this brief interaction, Barbara asked if I would be her boyfriend. This meeting determined the course of my career: although social work has been 'curiously inactive in the field [of deafblindness]' (Luey 1994:213) and there are few practitioners who specialise in sensory impairment, I went on to complete further academic and professional qualifications and became a specialist social worker for deafblind people.

Having spent ten years in social work practice, I left in 2010, and entered social work education; but my interest in social work with deafblind people has remained. As I began to research and teach in this field, my mind returned to Barbara; she will now be in her 70s. Much of my social work practice experience had been with adults acquiring deafblindness in later life, but what is it like to age with the impairment, like Barbara? I also reflected on my perception of her vulnerability: in an interaction of just a few minutes, Barbara expressed an interest in a relationship. She seemed to be very vulnerable, but is this how she felt? A brief review of international media publications found stories of deafblind people being victims of crime, financial abuse, physical and psychological mistreatment, and sexual abuse (see, for example, Ball 2005, Carvel 2006, BBC 2014, Traynor 2014, Pilat 2015, Deery 2015, Hartley-Parkinson 2017, and Pooran 2017). In England, it was the untimely death of the deafblind woman Beverley Lewis, that prompted Gloucestershire Social Services to establish an 'Adults at Risk Unit' and develop associated adult protection policy and procedures (Simcock and Manthorpe 2014). Perhaps understandably therefore, as Smithdas (1980:1016), a man who has aged with deafblindness, observes, 'it has been commonplace for individuals and agencies working with deafblind people to exercise a paternalistic, protective attitude toward them'. Nevertheless, while in social work practice, the deafblind people I met demonstrated high levels of independence, resilience, coping and strength. I often felt the representation of the individual as vulnerable perhaps reflected the perception of family members, health and social care professionals or that of the referrer, rather than the deafblind person themselves. My perceptions of deafblind people's vulnerability were challenged and I was curious as to their own experiences and views on the phenomenon.

Vulnerability is a complex and contentious concept (Fawcett 2009), and a clear definition of the term appears to be absent in the health and social care literature (Abley et al. 2011). Nevertheless, as it is intrinsically linked to an understanding of need, risk and the need for protection, it is essential for social workers and other human services professionals to understand the concept, particularly when involved in safeguarding work. As Whittington (2016) observes, in England, contemporary legal provisions endorse such work as a specified social work role. Impoverishing our understanding of vulnerability is the paucity of research on the lived experience of the phenomenon: what does vulnerability mean to those who experience it. This thesis presents findings from the first UK based study of vulnerability from the perspectives of older adults ageing with deafblindness, and explores the following research questions:

- What does ‘being vulnerable’ mean to those ageing with deafblindness?
- What do those ageing with deafblindness feel vulnerable to?

As little is known about those ageing with the impairment, a further research question explored is:

- What does ‘getting older’ mean to those ageing with deafblindness?

Thesis Structure

Chapter One: Background

Chapter One places the primary study in context, by providing an overview of the phenomena of deafblindness and vulnerability. It offers an analysis of the complexities of these terms, considers their position in English law and policy, and addresses the relationship between research and vulnerability.

Chapter Two: Literature Review

Chapter Two further contextualises the primary study by describing the method and presenting the findings of a systematically conducted review of the deafblind literature. It determines what is already known about deafblind people’s experiences of and views on old age and ageing, and what is known about their vulnerability.

Chapters Three, Four and Five: Methods

In his reflections on living with deafblindness, Murphy (1991:171) observes that ‘it is almost impossible to write about myself objectively, to see problems and difficulties of the dual handicap as a sighted-hearing person would see them’. Comparably, as a sighted-hearing person, it is impossible for me to view the world as deafblind person, and like the majority of studies on the condition, therefore, the research presented in this thesis is completed by someone without lived experience of deafblindness (Kyle and Barnett 2012). Nevertheless, in the three methods chapters, I outline how adopting interpretative phenomenological analysis (IPA) enabled detailed examination of lived experience, offering an understanding of ‘what it is like to stand in the shoes of’ the participants (Pietkiewicz and Smith 2014:8). Chapter Five focuses specifically on the role of British Sign Language interpreters in the study.

Chapter Six: The Participants and the Researcher

Chapter Six offers ‘pen pictures’ to introduce the eight participants and a pen picture of myself as researcher, outlining my positionality.

Chapters Seven, Eight and Nine: Findings

Chapters Seven, Eight and Nine present the findings of the study. These are presented as a narrative account and make use of extracts from interview transcripts to provide evidence for each theme.

Chapter Ten: Discussion

In Chapter Ten, the relationship between research findings and other literature is considered and I examine how the findings support and extend the existing body of knowledge, thus developing our understanding of the phenomena under study.

Conclusion

In the final section, the thesis is concluded and the implications of the findings for policy, practice and future research outlined. The strengths and limitations of the study are also acknowledged.

CHAPTER ONE - BACKGROUND

1.1 Introduction

The aim of this opening background chapter is to place the primary study in context. It explores the phenomena of deafblindness and vulnerability, and considers how they are relevant to social work by describing their position in English law and policy. Beginning with an analysis of the complexities of defining deafblindness, the heterogeneity of the deafblind population is then explained, before focusing on 'older deafblind people'. The causes of deafblindness are then presented, before the chapter addresses its prevalence, pointing out that a clear picture of the numbers of those ageing with the condition has not yet been determined. Next, the chapter outlines social care for deafblind adults in England, describing how contemporary legislation places statutory duties on local authorities in relation to the deafblind population in their area. Recognising that local authorities are not the sole agency in social care provision, organisations of and for deafblind people are then introduced. An overview of the literature on deafblindness is not provided here, as this is presented in Chapter Two.

In the second part of this chapter, the complex and contested term 'vulnerability' is explored, by considering how it has been defined and theorised about in the literature across various disciplines. How the concept has been defined and described in English law and social policy is then analysed; as safeguarding is a key function of social work (Whittington 2016), particular attention is paid to its place in safeguarding law and policy. Before concluding, the chapter addresses the relationship between research and vulnerability, outlining how the research community has defined 'vulnerable groups', and how research processes can render groups vulnerable. This section ends by highlighting the paucity of studies on the empirical realities of vulnerability from the perspectives of those who experience it and the consequent calls for such studies in order to develop our understanding of the phenomenon.

1.2 Deafblindness: Definitions, Aetiology and Prevalence

1.2.1 Defining Deafblindness

Deafblindness is a severe and complex human impairment (Bodsworth et al. 2011) and deafblind people have been described as 'among those most disabled by the norms of our society' (Department of Health 1997:7). This complexity becomes apparent when attempts are made to define, describe and identify the condition (Dammeyer 2010b). Although deprivation in use of the distance senses (sound and sight) is common to all deafblind people (McInnes 1999), the condition affects people in different ways (Simcock and Manthorpe 2020). Literature exploring the impairment offers neither an 'exact nominal definition' (Rönnberg et al. 2002:137) nor a definition upon which there is clear consensus (Dammeyer 2015). Even the World Health Organisation endorsed *International Classification of Functioning, Disability and Health (ICF*) (World Health Organisation 2001) is found to be limited as a descriptive tool when applied to deafblindness (Möller 2003).

Terminology in the field is complex and the term 'deafblind' may itself be misleading (Wittich and Simcock 2019). It implies that the impairment consists of combined profound deafness and total blindness; however, this level of impairment is rare and does not describe the majority of deafblind people (Moller 2003, Wittich et al. 2013). Research with deafblind people has also identified that few use the term themselves to describe their impairment, preferring such terms as 'dual sensory impaired', 'Deaf with visual impairment' or 'having vision and hearing difficulties' (see, for example, Barnett 2002, Miner and The Information Center for Acquired Deafblindness 2008). Many terms describing the phenomenon have therefore emerged (Wittich et al. 2013) and include, *inter alia,* the hyphenated term 'deaf-blind', 'dual sensory loss', 'multi-sensory impairment', and 'concurrent loss of hearing and vision function' (Enerstvedt 1996, Wittich et al. 2013, Department of Health 2014b). This varying nomenclature reflects not only the challenge of defining the impairment (Mar 1993, Smith 1993) but also the broad spectrum of people who can be considered ‘deafblind’ (Smith 1993). For the sake of clarity, in this thesis I largely use the term ‘deafblind’ to refer to the population, irrespective of the severity of the impairment or the timing of its onset; this term can be used to describe the continuum of combined hearing and sight loss (Wittich and Simcock 2019). Nevertheless, this is not to suggest that the population is easily summarised within one term (Simcock 2017a).

Deafblindness has clinical, legal and functional definitions (Dammeyer 2010b, Simcock and Manthorpe 2020). In clinical settings, measures of visual acuity, visual field and auditory thresholds are used to define and describe blindness and deafness (Dammeyer 2010b). Nonetheless, Dunlap et al. (1982) and Dammeyer (2010b) argue that assessments should be made of the individual’s level of functioning when determining the presence of deafblindness, in addition to any clinical vision and hearing tests. This functional assessment is particularly important where, owing to the presence of cognitive impairment or behavioural difficulties, accurate testing of vision and hearing is not possible (Rönnberg and Borg 2001); it also serves to ensure that behaviours are correctly identified as being an indicator of deafblindness rather than attributed to any other additional impairment or mental health difficulty (Carvill 2001, Moller 2003, Kiani and Miller 2010).

Combining the clinical and functional, the United States legal definition of ‘deafblindness’ refers to specific visual acuity, visual field and auditory thresholds, but adds that the dual impairment must have an impact on functioning, in relation to activities of daily living, psychosocial adjustment and vocational attainment, in order to meet the definition of ‘deafblind’ (Code of Federal Regulations, Title 34 396 4 (c), 2011). Other definitions place greater emphasis on the functional impact of the impairment and are less prescriptive regarding levels of visual acuity, visual field and hearing loss. For example, the definition adopted by the five Nordic countries (Denmark, Finland, Iceland, Norway and Sweden) in 1980, and subsequently revised in 2007, focuses on functional challenges (relating to difficulties in accessing information, work, education, social situations and family life) rather than clinical assessment of vision and hearing loss (Möller 2003, Danermark and Möller 2008, Göransson 2008). Such definitions are inclusive of those with some residual hearing and/or vision rather than exclusive to those with no functional ability in either sense (Brabyn et al. 2007, Gullacksen et al. 2011). The Nordic definition has had a global impact (Danermark and Möller 2008), with both national organisations (for example, the Australian Deafblind Council and Deafblind South Africa) and international organisations (for example, the European Deafblind Union and the World Federation of the Deafblind) adopting functional definitions.

In England, the Department of Health and Social Care (formerly the Department of Health) has adopted the working definition conceived by the Deafblind Services Liaison Group (see section 1.3.1), which it describes as the 'generally accepted definition' (Department of Health 2014b:5). This definition is used in English policy guidance on social care for deafblind children and adults (see section 1.3.1) and is therefore that adopted in this thesis. It states that persons are considered deafblind:

> if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility. This includes people with a progressive sight and hearing loss (Department of Health 2014b:5).

Focusing on functional difficulties rather than clinical assessment and thresholds, this definition implicitly acknowledges that people with some residual vision and/or hearing may still be considered 'deafblind' (Alley and Keeler 2009). It covers a broad spectrum of people (Roberts et al. 2007) including those with total loss of both senses and those with less severe hearing and sight impairments (Department of Health 2014b). The Department of Health (2014b) suggests that the term 'dual sensory loss' may be used inter-changeably with 'deafblind' as a way of reflecting the inclusivity of the definition.

Coppersmith (1982) offers a visual representation of the broad spectrum of people considered deafblind, identifying four groups:

Figure 1: ***The Coppersmith Matrix***

	HEARING	**HARD OF HEARING**	**DEAF**
SIGHTED	Hearing and Sighted	Hard of Hearing “Normal” Vision	Deaf “Normal” Vision
PARTIALLY SIGHTED	Partially sighted “Normal” hearing	Deafblind	
BLIND	Blind “Normal” hearing		

Although these four groups, or ‘dual sensory loss subpopulations (sic)’ (Brabyn et al. 2007:220) reflect the wide range of people who can be defined as deafblind, many working in the field consider deafblindness itself as a unique impairment, distinct from single sensory impairments (Alley and Keeler 2009, Deafblind UK 2009). There is evidence of international level consensus among specialist organisations over the use of the unhyphenated term ‘deafblind’ (rather than ‘deaf-blind’) in recognition that the impairment is a third distinct phenomenon, rather than simply the presence of both deafness and blindness (Lagati 1995, Jaiswal et al. 2018). However, the World Federation of the Deafblind (2018) reports that from the data available, only 37% of countries (n=50) recognise deafblindness as a distinct disability. Nevertheless, such recognition is evident in the European Parliament written declaration formally adopted by the European Parliament on 1st April 2004 (*Declaration on the Rights of Deafblind People* 03A_DN(2004) 04-01 PAR002). In England, a motion by the sub-committee on sensory impairment to recognise deafblindness as a third discrete sensory impairment was endorsed by the Association of Directors of Social Services (Alley and Keeler 2009).

While Schneider et al. (2011) report inconclusive findings relating to the presence and nature of any additional or interactive impact of dual over single sensory impairment, in their review of empirical studies, Saunders and Echt (2012) observe how the combined impairment often results in larger functional effects. The notion of synergy is a defining feature of this increased functional impact: the sum (deafblindness) is greater than the parts (hearing and vision impairment) (Brabyn et al. 2007, Hersh 2013b, Hämäläinen et al. 2018). A deafblind person in Alley and Keeler's (2009:26) *Deafblind Project Report* offers a more colourful description of this synergistic effect*:*

> If you think of deafness as the colour yellow and blindness as the colour blue, when you mix the two together you don't get yellow-blue but a completely different colour, green"

Deafblindness prevents a person from using one sense to compensate for the impairment in the other and therefore from functioning as a single sensory impaired person (Roberts et al. 2007, Hämäläinen et al. 2018). Even a relatively minor sensory impairment can have a significant impact on function when it exists in combination with another. For example, a minor visual impairment may pose limited difficulty for a hearing person; however, for a deaf or hard of hearing person who relies on lip-reading for receptive communication, such impairment would be particularly challenging (Roberts et al. 2007, Dawes et al. 2014). Nonetheless, determining the point at which one sense can no longer compensate for the other is yet to be realised (Wittich and Simcock 2019).

1.2.2 Deafblind People: A Heterogeneous Population

Deafblind people form a heterogeneous population. Such is the variation in the population, Smith (1993) argues that use of the single term 'deafblind' to describe the population as a whole is meaningless. Variations include age, age of onset, aetiology, interval between impairment in each sense, cognitive function, language and communication method, and cultural background (Dalby et al. 2009, Bodsworth et al. 2011, Simcock 2017b). Identification of different 'categories' of deafblind people within the population reflects this variation. One important distinction made is that between congenital deafblindness (onset of both hearing and sight impairment between birth and two to three years of age) and acquired deafblindness (onset of sight impairment, hearing impairment or both occurring later in life') (Rönnberg and Borg 2001, Dalby et al. 2009, Dammeyer 2013, 2014). There are significant differences between these categories (Dalby et al. 2009). For example, there is wide variation in the communication methods used (Dalby et al. 2009) and while communication poses difficulties for all deafblind people, it can prove uniquely challenging for congenitally deafblind people, who may experience difficulty understanding the very concept of language (Hart 2008). Additional learning disabilities (intellectual impairment), physical impairments and behavioural difficulties are more prevalent amongst congenitally deafblind people than those with acquired deafblindness (Carvill 2001, Rönnberg and Borg 2001, Dalby et al. 2009). The majority of adults with acquired deafblindness have intellectual ability 'within the normal range' (Bodsworth et al. 2011:19); nevertheless, acquired deafblindness has its own distinctive challenges, including the need for practical and psychological adjustment and the risk of increased social isolation (Brennan and Bally 2007, Dalby et al. 2009).

While helpful in understanding the condition, some argue that the distinction between congenital and acquired deafblindness is artificial (see, for example, Clark 1994, and Moller 2003). Those acquiring deafblindness before the acquisition of language (pre-lingually) may function in similar ways to those congenitally deafblind (Welsh Assembly Government 2008); there are also those with congenital syndromes which result in acquired deafblindness (National Consortium on Deaf-Blindness 2010). Dammeyer (2013) further classifies then those with acquired deafblindness into two groups: those whose deafblindness is a result of conditions associated with old age; and those who become deafblind earlier in their lives. Additionally, in the context of congenital impairment, Ask Larsen and Damen (2014) have developed the distinction further, adding the dimensions of diagnosis, whether onset time preceded the development of communication abilities, onset order relative to chronological age, and mobility and access to information abilities.

This work advances the earlier identification of four distinct groups of deafblind people by the Deafblind Services Liaison Group (1988), which are described in English social care policy (Department of Health 2014b:5):

1. those who are hearing and sight impaired from birth or early childhood;
2. those blind from birth or early childhood who subsequently acquire a hearing loss that has a significant functional impact;
3. those who are deaf from birth or early childhood who subsequently acquire a significant visual loss;
4. those who acquire a hearing and sight impairment later in life that has a significant functional impairment.

1.2.3 Older Deafblind People

In the English Department of Health (1997) good practice guidelines, *Think Dual Sensory*, the classifications noted above are extended and applied specifically to older deafblind people:

1. those whose deafblindness has been acquired and developed in old age;
2. older people who have lived with sight impairment and subsequently acquire hearing loss;
3. older deafened or hearing impaired people who have used speech to communicate, who subsequently acquire visual impairment;
4. older culturally Deaf people who use British Sign Language, who subsequently acquire visual impairment;
5. older people who have been deafblind for all or the majority of their life.

The majority of older deafblind people fall into the first of these groups (Munroe 2001, Robertson and Emerson 2010, Wittich et al. 2012); reflecting this demographic, the majority of studies with older deafblind people focus on those with late-life acquired deafblindness (Wittich and Simcock 2019). Nevertheless, it is those who have lived with deafblindness since birth or over a long period of time (groups two, three, four and five) that are the population of interest in this thesis. This is a smaller group of older deafblind people (Göransson 2008) and just as older Deaf sign language using adults (those Deaf from birth or early childhood) are largely absent in gerontological studies (Werngren-Elgström et al. 2006), bibliographic database searches using terms such as ‘older people’ and ‘deafblindness’ mainly lead to literature on late-life acquired dual sensory loss (see Chapter Two). As such, like other groups ageing with impairment (Jeppsson Grassman et al. 2012), those ageing with deafblindness are ostensibly a population yet to be fully explored (Simcock 2017a).

1.2.4 Aetiology: What causes deafblindness?

Deafblindness has a ‘range of aetiologies’ (Bodsworth et al. 2011:7), and rehabilitation professionals identify the development of our understanding of these as a research priority (Wittich et al. 2016). Specialist organisations of and for deafblind people identify between 40 (National Consortium on Deaf-Blindness 2010) and over 70 different causes (Deafblind UK 2009). For some deafblind people, the cause of their impairment remains unknown (Belote 2003, Dammeyer 2010b) .

Causes of congenital deafblindness include premature birth, birth trauma, foetal alcohol syndrome, a range of genetic disorders and intrauterine infections (Moller 2003, Dalby et al. 2009). Dammeyer (2010b) provides a detailed description of aetiologies of congenital deafblindness in Denmark, where the most frequent causes among those living into adulthood include Congenital Rubella Syndrome (CRS), Down syndrome, and complications related to prematurity. Although once a main cause of congenital deafblindness, CRS is now rare in countries with vaccination programmes (Cutts et al. 1997, Sullivan et al. 1999, Tookey 2004, Dalby et al. 2009). CHARGE syndrome, a chromosomal disorder resulting in additional learning disabilities and heart problems (Dalby et al. 2009) is now considered a leading cause of congenital deafblindness in the UK (Deuce et al. 2012).

Causes of acquired deafblindness include post-natal and early childhood infections, a range of hereditary syndromes, accident and trauma, acquired brain injury, various genetic syndromes and age-related conditions (Ronnberg et al.

2002, Moller 2003, Wittich et al. 2012). Many of those with late-life acquired deafblindness have combined sensory loss owing to the most common age-related sight loss condition, age-related macular degeneration, and age-related hearing loss (presbycusis): these conditions cause deafblindness, but are independent of each other (Wittich et al. 2012). The most common cause of deafblindness acquired earlier in life is the genetic condition Usher syndrome, an autosomal recessive disorder (Moller 2003, Wittich et al. 2012, Dammeyer 2013). There are three types of the condition: type I and II are characterised by congenital profound deafness (Type I) or hearing impairment (Type II) and progressive sight loss owing to retinitis pigmentosa (RP), manifesting in childhood or early adulthood; type III is characterised by progressive hearing and sight loss (as a result of RP), with onset in adolescence (Kimberling and Möller 1995, Miner 1995, Miner 1997, Kimberling and Lindenmuth 2006, Brabyn et al. 2007).

It is important to note the limitations of describing aetiologies as associated with congenital or acquired deafblindness. For some deafblind people, one impairment may be congenital, while the other is acquired (Wittich and Simcock 2019).

1.2.5 Prevalence: How many deafblind people are there?

Determining the prevalence of deafblindness is important; it can inform resource allocation, health and social care service planning, and also support research into the prevention, identification, and treatment of the condition (Wittich and Simcock 2019, Simcock and Manthorpe 2020). Nevertheless, establishing accurate prevalence rates is difficult (Roberts et al. 2007, Wittich and Simcock 2019). In part, this is due to the lack of a consistent definition, as outlined in section 1.2.1. The relatively small size of the population, communication difficulties when completing formal assessments and surveys, and limitations associated with self-reported impairment are also problematising factors (Göransson 2008, Robertson and Emerson 2010, Wittich and Simcock 2019). Additionally, deafblindness may be overlooked in adults with learning disabilities (Carvill 2001, Spring et al. 2012) and major public surveys do not necessarily record deafblindness as a third category of sensory impairment (for example, in the Department of Health 2000 Health Survey, visual and hearing impairment are listed separately). In England, the policy guidance requiring local authorities to identify and keep a record of deafblind people in their areas, as described in Section 1.3.1, has been interpreted and applied inconsistently (Sense 2010, Sense 2014, Simcock and Manthorpe 2014). As such, prevalence estimates differ considerably (Bodsworth et al. 2011) and further research has been advocated (Bodsworth et al. 2011, Simcock and Manthorpe 2020).

It is not suggested, however, that there is a complete absence of prevalence research: a range of prevalence studies has been undertaken (Bodsworth et al. 2011, Wittich and Simcock 2019). This includes studies examining the prevalence of deafblindness in certain countries (see, for example, Caban et al. 2005, Dammeyer 2010b, Spring et al. 2012, Heine et al. 2020), among adults with additional intellectual impairment (see, for example, Carvill 2001, Evenhuis et al. 2001), prevalence of a particular syndrome (see, for example, Lockett and Rudolph 1980, Boughman et al. 1983, Sadeghi et al. 2004), and deafblindness across age groups (see, for example, Horowitz et al. 2001, Killoran 2007). In the UK, determining prevalence rates has been the focus of much local authority research (Kyle and Barnett 2012). The two major charitable organisations for deafblind people based in the UK, Sense and Deafblind UK (see section 1.3.2) have also made various estimates of prevalence (Bodsworth et al. 2011). In a study commissioned by Sense, Robertson and Emerson (2010) offer detailed examination of the prevalence of deafblindness in the UK. Adopting a four-step process and drawing on existing national data sources, this research suggests a substantially higher figure than that of earlier UK government estimates: 356,000 deafblind people in the UK, 222,000 of whom are identified as over 70 years old. Similarly, although acquiring deafblindness before the age of 65 is estimated to be rare (Dammeyer 2013), Dawes et al. (2014) observe a greater prevalence rate of deafblindness than expected in UK adults aged 40 -69 years old, in their analysis of the UK BioBank dataset.

Overall consensus in the literature is that the prevalence of deafblindness increases with advancing age (Wittich and Simcock 2019). Nevertheless, determining the prevalence of the particular deafblind population of interest in this thesis, older people who have aged with the impairment, is problematic. One Danish study does note that 4.7% (n=190) of their congenitally deafblind participants were over the age of 60 (Dammeyer 2010b). Similarly, in their examination of the deafblindness rehabilitation population in Montreal, Canada, Wittich et al. (2012) observe that 20% of the older adults in this population were receiving services for the rehabilitation of congenital or progressive illnesses, such as Usher Syndrome. In the UK, Kyle and Barnett (2012) offer a rudimentary estimate of those born deafblind and those culturally Deaf acquiring sight loss later in life; however, only six of the deafblind participants in their study (n=20) were aged between 51-65 years at the time of the research, with no participants over 65 years of age included. Furthermore, while current age is noted in the Robertson and Emerson (2010) study, like other surveys examining disability in later life (Putnam 2012), the age at onset of the impairment is not, rendering it impossible to determine the prevalence rate of older people who have been deafblind for all or the majority of their lives. As such, a clear picture of the number of older people in the UK who have aged with deafblindness is not currently available. Nonetheless, although a smaller group of older deafblind people than those with late-life acquired impairment, like any 'ageing with' population, contemporary diagnostic and treatment advances may result in increasing numbers (Westwood and Carey 2018).

1.3 Social Care and Deafblind Adults

1.3.1 Social Care Law and Policy for Deafblind Adults in England

Writing from the USA, Luey (1994:213) observes that the social work profession has been 'curiously inactive in the field [of deafblindness]'. Nevertheless, in the UK, Alley and Keeler (2009) acknowledge that since the late 1980s there has been increased awareness of the unmet needs of deafblind people among public services. 1988 saw the publication of *Breaking through: Developing Services for*

Deafblind People (Deafblind Services Liaison Group 1988), a report authored by the Deafblind Services Liaison Group (a partnership of agencies concerned with raising awareness of the needs of deafblind people). This was followed by a Social Services Inspectorate (SSI) inspection of services for deafblind people in six local authorities, resulting in the publication of *Sign Posts: Leading to Better Social Services for Deafblind People* (Department of Health and Social Services Inspectorate 1989). Described by Alley and Keeler (2009:20) as 'groundbreaking', these two reports highlighted matters such as the importance of identifying deafblindness, and the need for specialist assessment and specialist communication support. However, 1989 also saw the untimely death of the Gloucestershire deafblind woman Beverley Lewis (Simcock and Manthorpe 2014) and a consequent increase in the concerns being raised by charitable organisations about statutory agencies' response to deafblind people (Wood and Leece 2003). Furthermore, older deafblind people had been largely ignored in the earlier reports; it was not until 1997, following a series of commissioned consultation seminars, that the Department of Health published *Think Dual Sensory: Good Practice Guidelines for Older People with Dual Sensory Loss* (Department of Health 1997). These guidelines predominantly focused on older people with late-life acquired deafblindness, but nonetheless placed deafblind people and their needs on the social care policy agenda.

A private members' Bill concerning deafblind people was introduced to the House of Lords by Lord Ashley of Stoke in January 2000 (Parliament House of Lords 2000). Although unsuccessful, this triggered further consultation and subsequent publication of the first statutory guidance on social care for deafblind people in England (Department of Health 2001), updated in 2009 (Department of Health 2009b). While this guidance was considered fundamental to improvements in social care for deafblind people (Waheed 2016), enactment of the Care Act 2014 (and its accompanying legal provisions) has resulted in explicit obligations towards deafblind people being placed on English local authorities. Reflecting the campaigning work of specialist organisations and deafblind people themselves during the passing of the legislation, deafblindness is mentioned more than 20 times in the accompanying *Care and Support Statutory Guidance* (Department of Health 2016).

Some of the legal duties are specific to deafblind people. For example, associated secondary legislation requires that a social care needs assessment relating to a deafblind adult, must be carried out by 'a person who has specific training and expertise relating to individuals who are deafblind' (*The Care and Support (Assessment) Regulations 2014 SI2014/2827: para.6.1*). The *Care and Support Statutory Guidance* sets out the appropriate level and minimum areas of this training and expertise (Department of Health 2016:para. 6.92 & 6.93) and also recommends the involvement of the assessing specialist in care and support planning (*ibid.:* para.10.34) and sign off of the proposed plan (*ibid.:* para.10.85). In other legal provisions, the needs of deafblind people are considered in relation to mainstream social care processes. For example, the *Care and Support Statutory Guidance* acknowledges that Resource Allocation Systems (RAS), used by some local authorities to determine the amount of funding necessary to meet an adult's needs, may be unsuitable for deafblind people, for whom care and support may be relatively more costly (Department of Health 2016: para.11.23).

Under section 78 of the Care Act 2014 (and section 7 of the Local Authority Social Services Act 1970 in relation to children), policy guidance entitled *Care and Support for Deafblind Children and Adults* (Department of Health 2014b), which further updated the guidance originally issued in 2001, was also published. This requires local authorities in England to do the following:

- Identify, make contact with and keep a record of all Deafblind people in their catchment area. [Akin to being registered as visually impaired, being 'recorded' as deafblind is voluntary. However, it does not automatically entitle the person to services or welfare benefits in the same way as registration as visually impaired];
- Ensure that when an assessment of needs for care and support is carried out, this is done by team or person with specific training and expertise relating to Deafblind persons – in particular to assess the need for

communication, one-to-one human contact, social interaction and emotional wellbeing, support with mobility, assistive technology and habilitation/rehabilitation [one-to-one human support is ordinarily that provided by ‘communicator-guides’, who exist globally under different names (for example, intervenors, guide-communicators, guide-helps, interpreter-guides, communicator-guides, and partners) (Hersh 2013a); they assist deafblind individuals with any functional activity];

- Ensure services provided to deafblind people are appropriate, recognising that they may not necessarily be able to benefit from mainstream services or those services aimed primarily at blind people or deaf people who are able to rely on their other senses;
- Ensure that Deafblind people are able to access specifically-trained one-to-one support workers if they are assessed as requiring one;
- Provide information and advice in ways which are accessible to Deafblind people; and
- Ensure that a Director-level member of local authority senior team has overall responsibility for Deafblind services (Department of Health 2014b:4).

Although there is evidence that earlier social care policy for deafblind people has been interpreted and applied inconsistently by local authorities (Sense 2010, Sense 2014, Simcock and Manthorpe 2014), at the time of writing, the position regarding impact of the Care Act 2014 and associated provisions is unknown. Nevertheless, in 2016, Sense undertook a rudimentary survey, in which they gathered data from their in-house legal team, in-house community managers and assessment and advice officers, and a small group of deafblind people (number not reported) (Waheed 2016). Survey findings reveal substantial progress in meeting deafblind people’s needs since these new legal and policy provisions came into force. However, they also show barriers in application: lack of awareness of the legal duties owed to deafblind people among social care practitioners; ongoing difficulties gaining access to specialist assessment; completion of assessments by unqualified staff; and the non-involvement of specialists in care and support planning, reviews and the sign off of plans (*ibid.*) Furthermore, while various UK public bodies have general responsibilities towards deafblind people, arising out of legal provisions such as the Equality Act 2010 and the Accessible Information Standard (NHS England 2017), Wood and Leece (2003) highlight that English law and policy place lead responsibility for meeting the needs of deafblind people on local authorities. This, they argue, diminishes other agencies' responsibilities, which is of particular concern for deafblind adults, in view of the common need for multi-agency support (Mar 1993, Lewin-Leigh 2000). The Care Act 2014 and associated provisions have not changed this position.

1.3.2 Organisations of and for Deafblind People

There are several international and national organisations of and for deafblind people. This includes 'umbrella' or co-ordinating organisations, such as the European Deafblind Network (EDbN) established in 1987, the World Federation of the Deafblind (WFDB) founded in 2001, and also Deafblind International (DbI), an international, not-for-profit membership organisation working to promote awareness of deafblindness and to influence appropriate service development globally. The provenance of such organisations is often found in shared concern about the needs of deafblind children, particularly their educational needs (Wittich and Simcock 2019); it was not until the 1980s that organisations became explicitly concerned with the needs of older deafblind people (*ibid.*).

In the UK, the two national deafblind organisations, Sense and Deafblind UK, have formal links with government and all party parliamentary groups, and contribute to policy consultations and campaigning (Jarrold 2014). Their 1990s joint campaign, 'Yes to Access', had a noteworthy role in raising awareness of the needs of deafblind people: it was a pivotal contribution to the process that led to publication of the first statutory guidance on social care for deafblind people in England (see section 1.3.1). Nevertheless, consultation and campaigning are not their only role. Both organisations also provide training and an information and advice service. Although local authorities may meet their statutory duties (see section 1.3.1) via direct service provision, they may also commission services from Sense and Deafblind UK. These include specialist assessment, communicator-guide and intervenor services, and care and support such as day and residential care. These services may also be purchased privately or by those making use of direct payments from local authorities (monies provided to eligible individuals in lieu of direct or commissioned services) to meet their care and support needs. Sense initially focused on congenitally deafblind children, reflecting its origins in the campaigning work of a small group of mothers of children born with congenital rubella syndrome (Sense 2019b). However, it now provides services to children and adults with congenital and acquired deafblindness, and most recently has broadened its remit to support those with ‘complex disabilities’ (Sense 2019a). Deafblind UK has predominantly been concerned about those with acquired deafblindness, including older people with late-life acquired deafblindness; nonetheless, their stated purpose is to ‘support people with combined sight and hearing loss’ (Deafblind UK 2020), which would include those congenitally deafblind.

Some UK based national organisations of and for single sensory impaired people also offer services to the deafblind population. For example, the Royal National Institute of Blind People (RNIB) offers advice and information on deafblindness (Royal National Institute of Blind People 2019), and Action on Hearing Loss (formerly the Royal National Institute for the Deaf: RNID) provides information and advice, assessment, home care and residential care services, and rehabilitation (Action on Hearing Loss 2019). At a local level, sensory impairment organisations may offer support to deafblind people in their area; for example, both the Essex based organisation ECL Sensory Support and the Leeds Society for Deaf and Blind People offer various deafblind services (Leeds Society for Deaf and Blind People 2019, ECL Sensory Service 2020). In addition to these institutions, there are organisations that are concerned with different sub-sections of the deafblind population. This includes those focused on specific conditions, such as the Molly Watt Trust, which aims to raise awareness of Usher Syndrome (Molly Watt Trust 2020), those focused on deafblind children and young people, such as the Leeds based organisation Sensory Linq (Sensory Linq 2019), and Usher Kids UK, an organisation for children with Usher syndrome and their families (Usher Kids UK 2017).

1.4. Vulnerability: Definitions, Law and Policy, and Research

1.4.1 Defining Vulnerability: a complex and contested term

Described by Brown (2011:313) as a 'popular term in the lexicon of every day life', vulnerability is a key concept in policy, law and professional practice. As a term frequently used by health and social care professionals (Fawcett 2009, Heaslip et al. 2016b), Brown (2012; 2017) argues that the concept is particularly relevant in the field of welfare. The way in which vulnerability is understood has a significant impact on both the relationship between practitioners and users of social care services and the approach taken to intervention (Fawcett 2009, Brown 2017). Reflecting its etymology from the Latin word *vulnus,* meaning 'wound' (Goergen and Beaulieu 2013) and dictionary definitions that refer to a predisposition to being hurt or attacked, in the context of social care, vulnerability has largely referred to the state of being susceptible to exposure to harm (Parley 2010). Simcock and Manthorpe (2014) suggest that a limited understanding of the term may result in risks of harm being overlooked. The term has generally, therefore, been applied to social care service recipients: children, older people and disabled people (Parley 2010). Nevertheless, Clough (2010) notes that the concept is used in other ways in social care: to describe a specific situation, environment or event.

Recurrent use of the term has established supposed and shared understandings of vulnerability (Brown et al. 2017), and maintained a view of the concept as 'objective, uncontroversial and having fixed meaning' (Fawcett 2009:473). However, it is a contentious and complex, multi-layered concept (Grundy 2006, Smith et al. 2010, Moxley et al. 2015), and the ambiguity and malleability of the term result in diverse use: it means different things, to different people, in different settings (Schröder-Butterfill and Marianti 2006, Schroeder and Gefenas

2009, Clough 2010, Brown 2017). Abley et al. (2011) observe a lack of clear definition in the health and social care literature, and although meaning can be dependent upon discipline (Brown et al. 2017) (as described above in social care for example), Brown (2011) cites research in social care settings that shows a lack of understanding among practitioners. She goes on to argue that the concept of vulnerability has been insufficiently analysed in the welfare field (Brown 2017).

Although there is an under-developed social sciences literature on vulnerability (Brown 2011), the phenomenon is a long-standing analytical concept in the environmental sciences, especially studies of natural disasters and their human impact (Schröder-Butterfill and Marianti 2006, Brown et al. 2017). Such analyses have explored not only the potential for harm, but also draw attention to the link with strengths, assets and people's ability to cope (Brown et al. 2017). Chambers (1989:33) definition captures this: vulnerability as 'exposure to contingencies and stress and difficulty with coping with them'. Consideration of how the state, institutions and professional practices can bolster people's coping capacity highlights resilience as a related concept to vulnerability (Goergen and Beaulieu 2013). In theorising about vulnerability, other concepts have similarly featured as its conceptual relatives (Brown 2017). For example, Clough (2010) observes how the term vulnerability is used interchangeably with risk. Described as being 'two sides of the same coin' (Beck 2009:178), it has been argued that one cannot explore vulnerability without considering risk (Parley 2010). Nonetheless, distinctions are made between the two phenomena (McCreadie 2002); Parley (2010), for example, describes risk as future possibilities and vulnerability as present experience. Exploitation is an additional conceptual relative of vulnerability (Goodin 1985). For example, Wood (1995) links the notions within his description of vulnerability as susceptibility to being *used* rather than being *harmed*.

Scholarly activity since the turn of the century reflects a 'renewed… theoretical interest in the concept of vulnerability' within different academic disciplines (Keywood 2017:89), resulting in the development of different models of the phenomenon (Heaslip et al. 2016b). In her review of the nursing literature, Spiers (2000) identifies two distinct approaches to vulnerability: etic and emic. An etic approach involves the objective identification, description and categorisation of people with particular needs as a 'vulnerable' or 'at risk' group, determined by external evaluation of such groups as having higher probability of health or social problems (*ibid.*). Fawcett (2009) argues that this perspective is particularly common in health care and social work. An emic approach is informed by the lived experience of the individual, rather than objective risk assessment based on normative standards (Spiers 2000). Notwithstanding the presence of risk factors, from this perspective, vulnerability is only experienced if people feel unable to withstand or cope with presenting challenge or threat (*ibid.*). Drawing on findings from a qualitative phenomenological study of the lived experience of vulnerability within the Gypsy Roma and Travelling community, Heaslip et al. (2016a) develop an 'etemic' perspective, arguing that combining, rather than contrasting, an etic and emic approach, enables practitioners to develop a fuller understanding of what it means for an individual to be vulnerable.

Within nursing literature, concept analyses are also drawn upon to define and describe the features of vulnerability, and report susceptibility, chance and exposure as key attributes (Purdy 2004). With a focus on older people, Brocklehurst and Laurenson (2008) argue that a deeper understanding of the phenomenon necessitates consideration of its causes and effects across different domains, including physical, psychological, spiritual and sexuality based vulnerabilities. In exploring the conditions that produce vulnerability among older people, Grundy (2006) highlights the significance of having a reduced capacity to cope with the challenges one faces in later life. Coping capacity is one of the 'domains that shape vulnerability', alongside threats, exposure and outcomes, in the framework for understanding vulnerabilities in old age developed by Schröder-Butterfill and Marianti (2006:12). Cullati et al. (2018) develop this work further, adding an 'inability to recover from stress' as a process in the experience of vulnerability in later life.

Debate and scholarship in critical legal studies and feminist philosophy have seen the emergence of the universal vulnerability approach (Brown 2011, Pritchard-Jones 2016), most notably Fineman's development of the 'vulnerability thesis' (Fineman 2008, 2012). Fineman (2008:1) argues that vulnerability is 'universal and constant, inherent in the human condition'. Although she acknowledges that individuals experience vulnerability differently, Fineman emphasises the ongoing presence of the possibility of harm befalling all people, such that they may become dependent, as a reality of the human condition (Fineman 2008, 2012). As such, she contends that attempts by society to eliminate vulnerability are futile, and argues that the state be responsive by providing assets to people that facilitate resilience, in ways that do not privilege some groups over others (*ibid.*). This conception of vulnerability as universal and inherent to all humanity contrasts with definitions focused on the identification of particular people as 'vulnerable groups', ordinarily those in need of additional care and support (Mackenzie et al. 2014a). Nevertheless, both have been subject to critique. The latter risks labeling certain people as vulnerable based solely on their inherent characteristics (for example age or impairment) and neglecting wider structural and environmental factors (Leece and Leece 2011, Wiles 2011, Mackenzie et al. 2014a, Keywood 2017). Disabled people and disability studies scholars have been particularly critical of this perspective, noting its consequences as the disempowerment, dehumanisation and 'othering' of disabled people (Marks 1999, Fawcett 2009, Smith et al. 2010, Crowther 2015, Lonbay 2018), and in an adult safeguarding context, victim blaming and the sanction of paternalistic and overly protective state intervention (Hasler 2004, Faulkner 2012, Brown et al. 2017, Clough 2017). The universal vulnerability approach is critiqued for having limited practical use, owing to definitional breadth and lack of clarity, especially concerning the unique and context specific needs of certain groups (Mackenzie et al. 2014a). For example, Kohn (2014) argues that the approach cannot offer suggestions for social welfare policy to address the challenge of allocating limited resources.

In seeking to integrate the two approaches described above, feminist ethicists Mackenzie, Rogers and Dodds have developed a taxonomy of vulnerability that simultaneously recognises vulnerability as an ontological condition of all humanity, while enabling specific forms of the phenomenon to be acknowledged (Rogers et al. 2012, Mackenzie et al. 2014b). The taxonomy identifies three different, yet non-discrete, sources of vulnerability: inherent, situational and pathogenic (*ibid.*). Inherent sources of vulnerability include characteristics such as age, health status, disability and gender, but also the extent of a person's resilience and coping capacity. Situational sources may be either short or long term, and are individual or group social, political, economic and/or environmental situations, which cause or exacerbate vulnerability. Rogers et al. (2012) offer the example of differing levels of state support in poorer and more affluent countries following damage to property as a result of flooding . A subset of situational sources is pathogenic sources: vulnerability owing to failures in relationships, policy and social support, or situations of oppression. The experience of vulnerability is actively constructed through the failure of society and the environment to respond adequately to both the inherent and the situational. This could include unavailable, inaccessible and inappropriate care and support services (Simcock 2017b), but also those situations having a somewhat iatrogenic effect: an intervention designed to reduce vulnerabilities that has the opposite effect of creating further vulnerabilities or exacerbating those the intervention seeks to reduce (Mackenzie et al. 2014a). Keywood (2017) commends the recognition of situational vulnerability because it highlights the inadequacy of adult safeguarding policy and practice centred on inherent vulnerability alone (see section 1.4.2). Viewing vulnerability as socially constructed stresses the ways in which political, social and economic processes contribute to its genesis and maintenance (Schröder-Butterfill and Marianti 2006) and social workers have been encouraged to assess vulnerable situations rather than define individuals as vulnerable (Moxley et al. 2015). Nonetheless, irrespective of the cause, vulnerability is defined as an embodied experience, and thus universal vulnerability is acknowledged (Mackenzie et al. 2014a).

Mackenzie, Rogers and Dodds' taxonomy also describes two different vulnerability states: dispositional and occurent (Mackenzie et al. 2014a, Rogers et al. 2012). The former concerns potential vulnerability: possible sources of harm not yet or not likely to be realised; and the latter concerns actual vulnerability, which requires immediate intervention to reduce or prevent harm (*ibid*.). This intervention may be limited or ongoing in nature. For example, in a situation of financial abuse, a limited intervention may involve securing compensation, while an ongoing intervention may be the establishment of continued support with money management, such as appointeeship or the establishing of a lasting power of attorney.

As described thus far, definitions of vulnerability and theorising about the concept have largely been concerned with identifying vulnerable groups, determining the causes of vulnerability, and describing its key attributes. Brown (2011) observes that the term vulnerable is less frequently used in a relational sense, when the specifics of what an individual is vulnerable to are identified. This could be, for example, ill health, disability, criminal activity, or abuse and harm. Nevertheless, all such definitions maintain an association between vulnerability, risk and the need for protection, and arguably, therefore, foster the view of vulnerability as solely negative, which Heaslip et al. (2016a:3) describe as the 'predominant discourse' in health care. Fawcett (2009) contends that the consequence of this exclusively negative conceptualisation of vulnerability in the context of social work is the presentation of those using services as passive and dependent, with an associated neglect of people's strengths and consideration of what matters to them.

In contrast, in the last decade, others have proffered more positive definitions of vulnerability. The philosopher Martha Nussbaum, social work academic Brené Brown and theologian Richard Rohr have all described being vulnerable as being open to one's true self and being open to others: having a willingness to be seen as one truly is (Brown 2013, Aviv 2016, Rohr 2016). Brown (2017) comments on the popularity of Brené Brown's work in particular, and it appears an approach to vulnerability concerned with knowing and allowing one's true self to be seen is evident in popular culture (see, for example, the work of online author and blogger Wood 2015). Furthermore, Mathews (2018) refers to theorists who argue that the vulnerability of disabled people is a strength, in that it promotes interdependency, connection, and mutuality in communities, and therefore the development of society. This is a perspective shared by the secretary-general for the World Federation of the Deafblind, Akiko Fukuda, who argues that her own vulnerability helps 'make our world a better place' (Kyodo News 2014). A positive perspective on vulnerability is also observed among nurses providing care to older people, who have described the experience as providing an opportunity for growth (Stenbock-Hult and Sarvimäki 2011). Such approaches have resulted in calls for people to accept and indeed embrace their vulnerabilities, rather than reduce or deny them (see, for example, Brown 2013, Brendel 2014, Rohr 2016, May 2017).

1.4.2 Vulnerability in English Social Care Law and Policy

The complexity of defining vulnerability challenges any notion that it is 'intuitively obvious who vulnerable adults are' (Mandelstam 2013:13). Nevertheless, notwithstanding the subjectivity evident in determining who is considered vulnerable (Brown 2012), English legal and social policy provisions provide certain definitions. Writing in 2008, Brocklehurst and Laurenson observe increased policy attention on vulnerability among older people and Morris (2015) notes ubiquitous use of the term in political discourse about disabled people over the last decade. Vulnerability is a key concept in a wide range of legislation, policy and practice guidance that seeks to identify and respond to the phenomenon (Fawcett 2009, Brown et al. 2017, Keywood 2017). For example, in the criminal justice system, special provisions are made for 'vulnerable witnesses' (see, for example, the Youth Justice and Criminal Evidence Act 1999), suspects who are 'vulnerable persons' (Home Office 2018), and 'vulnerable victims' (see, for example, the Domestic Violence, Crime and Victims Act 2004, which created the offence of causing or allowing the death of a vulnerable adult). In the context of homelessness, identifying an individual as vulnerable may also determine a priority need for housing (see, for example, the Homelessness (Priority Need for Accommodation) (England) Order 2002).

In adult social care, the concept of vulnerability has underpinned safeguarding policy and practice (Lonbay 2018), and being identified as vulnerable has provided access to services and support (Fawcett 2009, Brown 2017) and sanctioned state intervention and protection (Dunn et al. 2009, Brown et al. 2017). The first statutory guidance on adult safeguarding, *No Secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse* (Department of Health 2000) started what Keywood (2017) calls the 'vulnerable adult experiment'. Placing a duty on local authorities to develop multi-agency procedures relating to the protection of vulnerable adults at risk of abuse, the guidance defined a 'vulnerable adult' as:

> a person aged 18 or over who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation (Department of Health 2000: para. 2.3).

Therefore, vulnerability was explicitly linked to a need for social care owing to inherent characteristics such as old age or disability; structural and situational factors were neglected and being old or disabled was seen as a source of vulnerability in itself (Grundy 2006, Dunn et al. 2009, Killick and Taylor 2009, Keywood 2017).

As described in section 1.4.1, disabled people were particularly critical of this perspective, arguing that it reflected a medical model of disability, homogenised disabled people and sanctioned overprotective state intervention (Sherwood-Johnson 2013, Keywood 2017). It is also argued that such policy definitions foster ageist attitudes and risk practice in which being old becomes synonymous with being vulnerable (see, for example, Kohn 2014). Such approaches have been found to impact adversely on the involvement of older people in safeguarding processes (Lonbay 2018). In 2008, government launched a review of *No Secrets*, consulting with a wide range of stakeholders including social workers, police, voluntary welfare organisations and service-users and carers. Government's response to the review acknowledged widespread support among consultees to replace the term 'vulnerable adult' owing to its focus on inherent characteristics and neglect of situational factors (Department of Health 2009a). Although evident in other legislation (see, for example, the Domestic Violence, Crime and Victims Act 2004 and the Safeguarding Vulnerable Groups Act 2006), in their report on the reform of English adult social care law, the Law Commission proposed replacing the term 'vulnerable adult' with 'adult at risk' (The Law Commission 2011). Such proposals were congruent with the contemporaneous health and social care policy agenda focused on balancing protection from harm with the promotion of rights, autonomy, choice and control (see, for example, Department of Health 2010a, Department of Health 2010b, and Local Government Association and Association of Directors of Adult Social Services 2014). Consequently, the Care Act 2014, and accompanying statutory guidance, drop the term 'vulnerable adult' and replace it with 'adult at risk', defined as an adult who:

> has needs for care and support (whether or not the authority is meeting any of those needs), is experiencing, or is at risk of, abuse or neglect, and as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it (s42 Care Act 2014).

The first version of the Care and Support statutory guidance (Department of Health 2014c) maintained an explicit link between vulnerability and inherent characteristics and neglected situational causes of vulnerability. However, this was amended in the updated version (Department of Health 2016) as illustrated by the extracts below taken from case studies presented in the guidance:

> The perpetrators sought out Miss Y and others because of their vulnerability – whether that was ***because of their age, disability, mental illness***, or their previous history as a victim of abuse (Department of Health 2014c: para. 14.70; my emphasis)

became:

> The perpetrators sought out Miss Y and others because of their perceived vulnerability – whether that was ***because of their isolated situation and social circumstances coupled with age, disability mental illness***, or their previous history as a victim of abuse (Department of Health 2016: para. 14.83; my emphasis).

and:

> Mr. A is 24 and has autism and a mild learning disability… although Mr. A was not currently experiencing abuse or neglect, he remained highly vulnerable to abuse ***due to his disabilities*** (Department of Health 2014c: para. 14.85; my emphasis).

became:

> Mr. A is 24 and has autism and a mild learning disability… although Mr. A was not currently experiencing abuse or neglect, he remained highly vulnerable to abuse ***due to his being well-known in his area as someone as easy to manipulate*** (Department of Health 2016: para. 14.101; my emphasis).

Notwithstanding this change of terminology in contemporary adult social care legal provisions, it would be inaccurate to claim that the notion of the 'vulnerable adult' is nugatory in social work law and practice. The concept remains central to the scope and exercise of the inherent jurisdiction of the high court (Pritchard-Jones 2016). As a tool used in safeguarding adults practice, the inherent jurisdiction is a common law doctrine, enabling superior courts to intervene (by way of court orders) to protect people. It was originally used in relation to mentally incapacitated adults, but the provisions of the Mental Capacity Act 2005 have rendered this largely redundant. Nevertheless, the scope of the inherent jurisdiction has been extended to 'vulnerable adults', who although capacitated, are believed to be unable to make a free choice or decision owing to 'constraint… coercion or undue influence or… for some other reason' (Munby J. in Re SA (Vulnerable Adult with Capacity: Marriage) [2005] EWHC 2942 (Fam); para.77). In the case of Re SA, Justice Munby described a 'vulnerable adult' as someone:

> unable to protect him or herself against significant harm or exploitation, or who is deaf, blind, or dumb, or who is substantially handicapped by illness, injury or congenital deformity (*ibid.:* para. 82).

Reflecting the disability movement's critique of the definition of 'vulnerable adult' in *No Secrets*, legal academics have been critical of this conceptualisation of the 'vulnerable adult'. They argue that it reflects an outdated view of vulnerability, conflates vulnerability with old age and disability, and neglects structural and situational causes and experiential elements of vulnerability (see, for example, Dunn et al. 2008, Pritchard-Jones 2016, 2018, and Keywood 2017). Pritchard-Jones (2016) also suggests that such a definition fails to elucidate how an individual's age or impairment actually informs their experience of vulnerability. Consequently, there is a risk that older and disabled people subject to safeguarding processes are disempowered and 'victim-blamed' (Dunn et al. 2008, Pritchard-Jones 2016).

Maintaining that English law and social policy has largely failed to recognise how vulnerability is produced by the structural and situational, Keywood (2017) nonetheless argues that sources of vulnerability other than inherent characteristics are now being acknowledged, citing High Court inherent jurisdiction judgments that have eschewed Justice Munby's definition of a 'vulnerable adult' described above. Similarly, Lindsey (2016) contends that the language of the Care Act suggests that the law is promoting a more nuanced understanding of vulnerability. Nevertheless, others are less optimistic. For example, Clough (2017) and Pritchard-Jones (2018) observe that a direct association between impairment (an inherent characteristic), a consequent need for care and support, and vulnerability remains in the Care Act 2014: an adult at risk is someone who needs care and support and is unable to protect himself or herself *as a result of* those needs. Therefore, despite calls to abandon the language of vulnerability in disabled people's human rights campaigning (see, for example, Clifford 2014, Crowther 2015, Morris 2015, and Novis 2015), it appears that 'treating the correlation between disability and vulnerability as inevitable [in legal and policy discourse] may prove irresistible' (Keywood 2017:89).

1.4.3 Research and Vulnerability

Qualitative research in social work often explores the lives and experiences of 'vulnerable groups' (Dominelli and Holloway 2008). Although any research participant or group of participants may be vulnerable (Ali and Kelly 2012), the perception that some people are particularly vulnerable is a 'predominant view in research' (Scully 2014:205). People are invariably identified as vulnerable in processes for securing ethical approval, and such identification, as evident in research codes of ethics, is associated with inherent characteristics (Connolly 2003, Dominelli and Holloway 2008). As such, the perception of children, disabled people, older people, homeless people and other marginalised groups, such as refugees and those with substance misuse difficulties, as vulnerable appears to be axiomatic (Ali and Kelly 2012). However, the complexity of vulnerability is increasingly explored in research ethics literature (see, for example, Levine et al. 2004, Liamputtong 2007, and van den Hoonaard 2018) and the fact that vulnerability may be merely assumed owing to one's inherent characteristics is acknowledged (see, for example, Wiles 2006:285, who refers to 'so called' vulnerable groups and 'the assumed vulnerability of members of groups'). The risk of excluding certain groups from participating in research owing to an assumption of vulnerability, has also been highlighted (Smith 2008).

Other researchers have explored how the research process itself may render people vulnerable (Sinding and Aronson 2003, Ali and Kelly 2012). For example, in her study with older people, Hey (1994) describes how an assumption of vulnerability had the potential to disempower participants. Connolly (2003) and Sinding and Aronson (2003) explore how discussions and interviews about sensitive topics may heighten participants' concerns and reinforce felt vulnerability. Similarly, ending involvement with some participants may exacerbate feelings of loneliness and emphasise social isolation (Sinding and Aronson 2003), a consideration in this study (see Chapter Three, section 3.4.7). Research may also reinforce assumptions of the vulnerability of certain groups (Shaw 2008). Indeed, I was aware of the risk of further reinforcing the notion of all deafblind lives as vulnerable lives by undertaking this study. Despite such concerns, it is not only study participants who may be affected by the research process. van den Hoonaard (2018:308) contends that the researcher 'might be the more vulnerable party' in qualitative research. Experiencing my own vulnerabilities in the course of this study is described in Chapter Three, section 3.4 and Chapter Ten, section 10.2.3.

As noted in section 1.4.1, vulnerability is a well-established analytical concept in environmental science research, and interest in the phenomenon has seen something of a renaissance across different academic disciplines. Nevertheless, Brown (2011:319) argues that it is 'time to sharpen up the research agenda on vulnerability'; this has particular relevance to gerontological and social work research, as vulnerability has been identified as a fundamental concept in analyses of the phenomenon of elder abuse (Goergen and Beaulieu 2013). Some studies of the lived experience of vulnerability do exist. For example, Abley et al. (2011) explore the views of older people on vulnerability, Høy et al. (2016) investigate the meaning of the concept for care home residents in Scandinavia, and Heaslip et al. (2016b) examine the lived experience of vulnerability among Gypsy, Roma and Travelling communities (noted in section 1.4.1). Such research has identified significant differences between the perspectives of professionals and older and disabled people on vulnerability: in particular, for older and disabled people, vulnerability is described as experienced in specific situations, whilst for health and social care professionals, vulnerability is related to the presence of certain inherent characteristics (see, for example, Abley et al. 2011, Leece and Leece 2011). Notwithstanding the existence of such studies, Brown et al. (2017) argue that research has predominantly concentrated on policy analysis and theoretical debate (see section 1.4.1), and has paid less attention to the lived experience of vulnerability from the perspectives of particular groups. An emic perspective is less explored than the etic perspective (Heaslip et al. 2016b) and older people have not always been involved in studies that seek to explore the concept (see, for example, Lonbay 2018). As such, there have been calls for further research on the empirical realities of vulnerability from the perspectives of those who experience it, in order to develop our understanding of the phenomenon (see, for example, Hoffmaster 2006, Wiles 2011, Tong 2014, Pritchard-Jones 2016, Keywood 2017). That understanding vulnerability requires an examination of what it means to experience it is emphasised by Hoffmaster (2006:44), who quotes the psychotherapist Rollo May: 'We cannot know vulnerability except as we feel vulnerability'.

1.5 Conclusion

Deafblindness is a complex impairment with many different causes. The deafblind population is heterogeneous and although the experience of deprivation in use of the distance senses (sound and sight) is shared, the condition affects people in different ways. Consequently, several terms are used to describe the phenomenon and various legal, clinical and functional definitions exist. In this thesis, I predominantly use the term 'deafblind', irrespective of the severity of the impairment or the timing of its onset and I use the functional definition found in English statutory guidance: combined sight and hearing impairment that causes difficulties with communication, access to information, and mobility. This statutory guidance accompanies both the Care Act 2014 and an associated set of regulations, which set out duties on English local authorities relating to the identification of deafblind people, and the assessment and meeting of their care and support their needs.

Older deafblind people were largely ignored in policy until the late 1990s, perhaps reflecting the origins of campaigning organisations, which are found in shared concern about the educational needs of deafblind children. Nevertheless, overall consensus in the literature is that the prevalence of deafblindness increases with advancing age. The majority of older deafblind people are those with late-life acquired deafblindness. Resembling other groups ageing with impairment, much less is known about those ageing with deafblindness; this includes the current unavailability of a clear picture of prevalence rates. As such, this is a group yet to be fully explored and therefore the group of interest in the primary study reported in this thesis.

Vulnerability is a similarly complex and contested term. It is nonetheless a key concept in a wide range of legislation, policy and practice guidance, including that concerned with safeguarding adults; it is also a term frequently used by health and social care professionals. Definitions have focused on the identification of 'vulnerable groups' through the external evaluation of risk, examination of the key attributes of the phenomenon, and analysis of its relationship with the concepts of risk, exploitation and resilience. Theoretical interest in vulnerability is found in literature across academic disciplines and two core conceptualisations are evident: vulnerability as universal and inherent in the human condition; and vulnerability as a way of identifying particular groups susceptible to specific harms or threats. Both these conceptualisations have been critiqued: the former as having limited practical use, especially in informing social welfare policy; the latter as labeling certain people as vulnerable based solely on inherent characteristics, and in an adult safeguarding context, for victim blaming and for sanctioning paternalistic and overly protective state intervention.

In seeking to integrate these two approaches, Mackenzie, Rogers and Dodds developed a taxonomy of vulnerability that identifies three different, yet non-discrete, sources of vulnerability and describes two different vulnerability states. Nevertheless, similar to other descriptions, such an approach maintains a solely negative view of vulnerability. In the last decade, others have proffered positive definitions of vulnerability: the state of being open to one's true self and being open to others. Such approaches have led to calls for people to accept and indeed embrace their vulnerabilities.

Parley (2010:267) observed that a 'clear unambiguous definition [of vulnerability] remains elusive', and this appears still to be the case. It is therefore unsurprising that there have been calls for clearer definitions of the concept in research (Brown et al. 2017). However, I desist from adopting a specific definition in this thesis, responding to observations of incongruence between participants' views and understandings of vulnerability and those of researchers (see, for example, Russell 1999, Foley 2012). Furthermore, vulnerability research has paid less attention to the lived experience of vulnerability from the perspectives of particular groups; there have been consequent calls for further research on the empirical realities of vulnerability from the perspectives of those who experience it, in order to develop our understanding of the phenomenon. Such research is the focus of the primary study reported in this thesis. Before explaining the methods adopted and presenting the findings, the next chapter describes a systematically conducted review examining what is already known about both the experiences of those ageing with deafblindness and the vulnerability of deafblind people, to further contextualise the research.

CHAPTER TWO - LITERATURE REVIEW

2.1 Introduction

While there is a body of interdisciplinary research on life transitions (Barroso et al. 2003) and a developing interest in those ageing with disability (Jeppsson Grassman et al. 2012), there is a dearth of research on the experiences of those ageing *with* deafblindness. Furthermore, while deafblind people have been described as 'some of the most vulnerable members of our community' (Hutton 2000:3), no published research specifically exploring the experience of this vulnerability, from the perspective of deafblind adults themselves, currently exists. Nevertheless, there are some primary studies, theoretical articles, practitioner papers, autobiographical and biographical material, and narrative accounts examining these phenomena. This literature review chapter, the findings of which have been published elsewhere (Simcock 2017a, Simcock 2017b: see Appendices A and B), identifies, analyses and synthesises this material. In doing so, it places the primary research reported in this thesis in the context of what is already known and identifies the knowledge gaps that the study aims to address. First, I outline and justify my approach to reviewing the literature; this includes reflecting upon the challenges that were encountered when completing the work, describing how they were managed and acknowledging any consequent limitations of the review. Following the customary structure of a systematic review, I offer an overview of the background literature on deafblindness, followed by a description of the aim and rationale of this review and the methods adopted. This is followed by presentation of the review findings and a discussion on how these relate to other studies and wider theorising on the phenomena, before the chapter concludes.

2.2 Adopting a Systematic Review Approach

Described as a 'cornerstone of evidence-based policy and practice' (Fisher et al. 2006:vi), systematic reviews use rigorous methods to identify, appraise and synthesise all available literature to answer a predefined focused question (Bryman 2008, Killick and Taylor 2009, Gough et al. 2012). Although not a systematic review in its fullest sense, this literature review follows key systematic review principles and draws on the Social Care Institute for Excellence (SCIE) systematic review guidelines (Rutter et al. 2010) and the Evidence for Policy and Practice Information and Co-coordinating Centre (EPPI Centre) methodologies as adapted by Imogen Taylor et al. (2006).

Originating in medical research (Victor 2008), systematic reviews traditionally focused on effectiveness studies (Dixon-Woods et al. 2006, Bryman 2008), synthesising quantitative data, predominantly from randomised controlled trials (Killick and Taylor 2009). They are now increasingly used in other disciplines, including social policy and social care (Fisher et al. 2006, Bryman 2008). Both the EPPI Centre and SCIE have advanced systematic review methodologies, developing approaches to synthesising qualitative studies (Barroso et al. 2003, Bryman 2008, National Institute for Health and Care Excellence 2013) and increasing the range of literature included within reviews (Fisher et al. 2006, Killick and Taylor 2009), to address a broader range of research questions (Oliver et al. 2005); this includes 'views/experiences' questions such as those presented in this chapter. A range of such systematic reviews is evident in the social work field (see, for example, Fisher et al. 2006, Shaw et al. 2009 and, Braye et al. 2011).

I have substantial experience of working with deafblind people. It was therefore important that the review moved beyond an analysis of what was 'already known' professionally, to one which provided 'as complete as possible a picture of the knowledge available' (Fisher et al. 2006:1). Although systematic reviews are not always the 'better way of dealing with the literature' (Bryman 2008:94), there were, nonetheless, persuasive reasons to adopt systematic review principles. First, use of a clearly focused research question reduced the risk of homogenising the deafblind population. Secondly, systematic review processes, including use of a rigorous search strategy, reduce the risk of publication bias (Killick and Taylor 2009) and assist in capturing user testimony: the knowledge derived from those using or having experience of social care services, considered a core element of SCIE systematic reviews (Rutter et al. 2010). Finally, systematic reviews have been shown to better highlight gaps in the evidence-base and point to further research questions (Waganaar 1999, Killick and Taylor 2009, Gough et al. 2012).

2.2.1 Challenges and Limitations

Despite the advantages described, adopting systematic review principles posed practical and methodological challenges. Aveyard (2007) observes that systematic reviews require a range of skills and are both time-consuming and labour intensive. The first challenge was to develop my skills in searching, appraising and synthesis, achieved by completing an EPPI Centre course. While the course was invaluable, it highlighted additional practical challenges. The EPPI Centre recommends the establishment of a review team, including an information specialist. SCIE also makes this recommendation, suggesting that the team should also include practitioners, policy makers, experienced systematic reviewers and topic experts (Rutter et al. 2010). SCIE adds that data extraction and quality appraisal, elements key to systematic reviewing, should be undertaken by at least two team members (*ibid.*). Resources to meet these recommendations were not available, and therefore the consequent limitations of this review are acknowledged. However, strategies suggested by Bryman (2008) for those lacking such resources proved useful. For example, contact with PhD supervisors, authors of relevant papers, and practitioners in the deafblind field, and a meeting with the information specialist at the EPPI Centre all assisted in developing a comprehensive search strategy. Furthermore, accurate record keeping during the search phase ensured transparency in the process.

Systematic reviews are no longer limited to the meta-analysis of quantitative studies, and methodologies for synthesising qualitative studies (Harden et al. 2004, Fisher et al. 2006) and mixed methods syntheses (Harden and Thomas 2005, Oliver et al. 2005) have emerged. These counter previous critiques that systematic reviews require the reviewer to adopt a positivist rather than interpretivist epistemological position (Harden and Thomas 2005).

Nevertheless, a preliminary scoping search of 12 bibliographic databases identified few topic relevant primary studies; what emerged was a highly diverse body of material. This finding reflects Pawson and colleagues' (2003) classification of the types and quality of knowledge in social care: organisational knowledge, practitioner knowledge, user knowledge, research knowledge, and policy community knowledge. Dixon-Woods et al. (2006:36) argue that orthodox systematic review methods could be considered 'ill-suited' to such diverse types of literature. In particular, two fundamental aspects of the systematic review process pose challenges: quality appraisal and synthesis.

Considered an essential stage in systematic reviewing, quality appraisal ensures the reliability of the studies included (Bryman 2008); where the review's purpose is to inform policy and practice, many argue that only high quality evidence should be included (Brian J. Taylor et al. 2006). This requirement posed two dilemmas: determining what constitutes evidence for the purpose of this review; and determining a suitable approach for the quality appraisal of that evidence, from the various tools available (Victor 2008). Some systematic reviews reject non-research and journalistic material (Barroso et al. 2003), but an approach based on a 'hierarchy of evidence' was rejected. Such approaches are considered inappropriate in reviews exploring views and experiences in the 'real world' (Brian J. Taylor et al. 2006) and would have reduced the amount of material included such that synthesis would not be viable. Furthermore, such an approach would have resulted in the exclusion of practitioner knowledge and user testimony. Acknowledging that 'there is no current consensus in social care as to what constitutes evidence' (Rutter et al. 2010:12), SCIE advise that all types of knowledge should be included, particularly user testimony (*ibid.*). Although such knowledge may be undervalued as evidence (Pawson et al. 2003), there is increasing recognition of the importance of user perspectives in systematic reviews (Gough et al. 2012). Owing to an apparent absence of voices of people ageing *with* disability in the disciplines of social gerontology, disability studies and gerontological social work (Minkler and Fadern 2002, Jeppsson Grassman et al. 2012), I decided to include user testimony in its various forms (for example, narrative accounts, opinion pieces, and auto-biographical material).

Having made the decision not to exclude material on the grounds of type of knowledge, it was necessary to determine an appropriate quality appraisal method. While various tools for the appraisal of qualitative studies exist (see, for example, the Critical Appraisal Skills Programme (CASP)(Public Health Resource Unit 2010), the Long et al. (2002) Evaluation Tool for Qualitative Studies and the McMaster Critical Review Form-Qualitative Studies (Letts et al. 2007)), quality standards for user testimony are uncommon (Pawson et al. 2003). Dixon-Woods et al. (2006), Killick and Taylor (2009) and Ploeg et al. (2009) all found it necessary to 'relax' quality criteria, in order to incorporate the material in the review. As the material I found reflects Pawson and colleagues' (2003) knowledge type classification, the TAPUPAS (Transparency, Accuracy, Purposivity, Utility, Propriety, Accessibility and Specificity) framework they suggest appeared an appropriate quality appraisal model (see section 2.5.3). Nevertheless, as suggested by Bryman (2008), appraisal focused predominantly on relevance to the review question rather than methodological quality.

Followed by dissemination of the findings, an explicitly defined process of synthesis is the penultimate stage of the systematic review (Killick and Taylor 2009). However, the diversity of material found posed challenges for such a synthesis. The nature of the review question suggested that a configurative and interpretative rather than aggregative approach would be appropriate (Bryman 2008, Victor 2008). The limited number of similar primary empirical studies identified rendered meta-ethnography inappropriate (Dixon-Woods et al. 2006). Therefore, this review draws on principles of critical interpretive synthesis developed by Dixon-Woods et al. (2006). Such an interpretative synthesis is not restricted to qualitative studies, but is possible on all forms of evidence (*ibid.*). In this approach, rather than being a determiner of whether material should be included or excluded, critique of the literature is offered within the synthesis as a feature of the synthesis and subsequent theory building.

2.3 Background Literature

2.3.1 Research Literature on Deafblindness

Writing in 2001, Rönnberg and Borg (2001:74) observe that '[f]rom an international perspective, the population of deaf-blind [had] received little research attention'. There is a paucity of literature on both the impairment and its consequences (*ibid.*). Despite the increased risk of early onset impairment in low and middle-income nations (Westwood and Carey 2018), in their scoping review of global deafblind literature, Jaiswal et al. (2018) note a particular dearth of literature about deafblind people in such countries. This knowledge gap is also highlighted by the World Federation of the Deafblind in their 2018 global report, which drew on data from the largest ever population-based study of deafblind people, a review of current literature, case studies, and Sense International surveys (World Federation of the Deafblind 2018). Jaiswal et al. (2018) also report a lack of qualitative inquiry into deafblind people's experiences, and there are specific calls for such research (Schneider et al. 2011, Tiwana et al. 2016). A lack of qualitative research on the experiences of deafblind people in the UK in particular is also recognised (Kyle and Barnett 2012). Consequently, writing over a decade after Rönnberg and Borg, Dammeyer (2015) maintains that research in deafblindness remains in its infancy.

Difficulties with recruitment, methodological challenges, struggles to secure funding, and the absence of a cohesive research community interested in the field are all cited as potential reasons for the limited number of studies (Brennan and Bally 2007, Wittich and Simcock 2019). Furthermore, Roy et al. (2018: 72) observe the absence of good practice guidance for engaging deafblind people in research, and argue that 'processes rely on methodologies that assume participants have full use of all their senses and that they are part of a hearing and sighted world'. Irrespective of the reasons, our understanding of the impairment, its impact and the experiences of those who have the condition and their families is adversely affected by this research gap. Moreover, Simcock and Wittich (2019) argue that lack of research knowledge is a consequence and possible contributing factor to deafblind people's exclusion from decision-making processes, development programmes, and participation in political and public life.

Notwithstanding this reported paucity of research, published studies do exist. These tend to focus on certain groups of deafblind people in particular circumstances (World Federation of the Deafblind 2018). This includes, for example, studies of those with additional intellectual impairment/learning disability (see, for example, Carvill 2001, Kiani and Miller 2010 and, Bloeming-Wolbrink et al. 2012), research on the use of cochlear implantation by deafblind people (see, for example, Arauz et al. 1997, Soper 2006, Dammeyer 2009 and, Carr et al. 2011), inquiry into the experiences of those with particular conditions (see, for example, Forrest et al. 2002, Bernstein and Denno 2005 and, Ellis and Hodges 2013a), and examination of communication difficulties, methods and strategies (see, for example, Reed et al. 1995, Heine and Browning 2002 and, Yorkston et al. 2010). There is also a body of clinical research into deafblindness aetiologies (Gullacksen et al. 2011) and a range of prevalence studies (see Chapter One, section 1.2.5).

Just as organisations of and for deafblind people have their origins in shared concern about deafblind children (see Chapter One, section 1.3.2), the research community adopted a similar approach (Wittich et al. 2016). Studies initially focused on the needs of deafblind children, and research concerning older deafblind people did not emerge until the 1980s (*ibid.*). The majority of this work focuses on those people with late-life acquired deafblindness; this reflects the demographic changes of ageing societies (Wittich and Simcock 2019). A systematic review of the literature on comorbidities and outcomes associated with deafblindness in older adults (Heine and Browning 2015) identified 42 papers concerned with this population. These papers report on research adopting a range of methodologies, including cross-sectional design and longitudinal studies.

In their narrative review of the literature on older deafblind people, Simcock and Wittich (2019) argue that the existing research demonstrates that older deafblind people are being 'left behind' in benefiting from implementation of the UN Principles for Older Persons. Studies also identify various psychosocial consequences of the impairment for older people, which are described as serious (Heine and Browning, 2004), wide-ranging (Brennan and Bally, 2007) and having the potential to impact on individuals' well-being (Dean et al, 2017). For example, Heine and Browning (2004) and Pavey et al (2009) report that older deafblind people experience communication difficulties that resulted in embarrassment, anxiety and fatigue. Difficulties maintaining independence by completing activities of daily living (ADL) and instrumental activities of daily living (IADL) are also observed among the older deafblind population in the USA (Brennan et al. 2005), Northern Europe (Lupsakko et al. 2002, Grue et al. 2009), Japan (Harada et al. 2008) and the UK (Tiwana et al. 2016). Additional age-related impairments and health problems complicate these difficulties (*ibid.*). In the first known study examining older couples' sexual activity where one spouse has acquired deafblindness, Lehane et al (2016) identify reduced sexual activity and lower levels of sex life satisfaction.

Dean et al. (2017) assert that there is an increasing body of evidence that deafblindness has a negative impact on quality of life, specifically health-related quality of life. Older people with deafblindness also self-report poorer health (Crews and Campbell 2004, Tiwana et al. 2016). Whether older deafblind people are at greater risk than the general population of poor mental health is hard to determine (Wittich and Simcock 2019). Psychological assessment of deafblind people is complex (Bodsworth et al. 2011), and when considering the research relating to depression among deafblind people, for example, both Chou (2008) and Hersh (2013a) highlight mixed findings. Nonetheless, studies adopting both self-reporting and objective measures of impairment and health status note greater frequency or increased risk of depressive symptoms amongst deafblind people than those without the impairment, even after controlling other significant covariates for the condition (Schneider et al. 2011, Guthrie et al. 2016b, Cosh et al. 2018). Higher rates of cognitive impairment among older deafblind people are also observed (Lin et al. 2004, Fisher et al. 2014, Guthrie et al. 2018). Such findings suggest that those with dual sensory loss are at increased risk of emotional, psychological and mental health problems.

Gaspar et al. (2017) maintain that our understanding of the experiences of those with acquired deafblindness remains impoverished. Despite the increase in studies on late-life acquired deafblindness, Simcock and Manthorpe (2020) highlight that few researchers have involved older people who are ageing with the condition. It is therefore the experiences of those who have aged or are ageing with deafblindness in particular, about which very little is known. As noted in Chapter One, this reflects the observation of Jeppsson Grassman and colleagues (2012) that little is known about the experiences of people ageing with a range of impairments. Some studies do exist, and these identify important differences between the 'ageing with disability' and 'ageing into disability' populations. However, such research has largely focused on those with physical impairments (see, for example, Zarb and Oliver 1993 and, Gilson and Netting 1997) or learning disabilities (see, for example, Gangadharan et al. 2009, Bigby and Haveman 2010 and, Kåhlin et al. 2013) and not sensory impairments, though one of Jeppsson Grassman et al. (2012) studies related to adults ageing with visual impairment. As such, a need for further inquiry into the experiences of those ageing with deafblindness is noted. This includes calls for research into changing clinical needs (Dalby et al. 2009) and the experiences of specific deafblind: those born with congenital rubella syndrome during the 1960s rubella pandemic (Armstrong and O'Donnell 2004) and those with Usher syndrome (Damen et al. 2005, Ellis and Hodges 2013a).

In addition to the general dearth of research in the field, existing studies are described as being of variable quality (Saunders and Echt 2007, Heine and Browning 2015). Brennan and Bally (2007) contend that research methodologies neglect the synergistic impact of deafblindness, described in Chapter One (see section 1.2.1). Tiwana et al. (2016) draw attention to the reliance of self-reported sensory impairment, and small sample sizes consisting of older people known to specialist organisations. A particular critique of current research is the failure of study authors to make explicit the specific sub-group of the deafblind population concerned. Combined with a lack of consensus on terminology for deafblindness, differing definitions, and varying methods of vision and hearing assessment, this renders synthesis of material, and the ability to draw conclusions from it, problematic (Dammeyer 2015, Tiwana et al. 2016, Simcock 2017a).

2.3.2. Non-Research Literature on Deafblindness

In addition to the published research literature, is material produced for and authored by specialist practitioners. This includes that related to the development and education of deafblind children (see, for example, McInnes and Treffry 1993 and, McInnes 1999), textbooks for sensory impairment rehabilitation professionals (see, for example, Sauerburger 1993), and guides for hands-on care workers in the social care sector (see, for example, Butler 2004a).

Autobiographical and biographical material also exists. This records the lives of famous deafblind people such as Laura Bridgman, known as the first deafblind person to be successfully educated in English Language (Gitter 2002), Helen Keller (Keller and Berger 2004) known as the first deafblind person to be educated to degree level, and the deafblind poet Jack Clemo (Clemo 1988). There is also autobiographical literature by deafblind people who, while less famous, otherwise have a somewhat 'public profile' (see, for example, Axelrod (2006) charting the life and ministry of the deafblind Roman Catholic Priest Father Cyril Axelrod, and Girma (2019), a memoir written by the first deafblind graduate of Harvard Law School). Although Gaspar et al. (2017:108) describe the publication of Helen Keller's autobiography as 'a major landmark in deafblindness history', as Bjorling (1981) notes, it is important to be mindful that these people are not representative of the majority deafblind population.

2.4 Aim

The aim of this review is to synthesise existing knowledge about the experiences of older people ageing with deafblindness and the phenomenon of vulnerability among the deafblind population. An initial scoping search of 12 bibliographic databases (between December 2012 and February 2013) helped refine the review question and inform the search strategy. The final review questions are:

- **What is known about the experiences, views and key features of old age and ageing for deafblind people?**
- **What is known about the vulnerability of deafblind people?**

2.5 Method

As noted in section 2.2 the review approach has been informed by EPPI-Centre methodologies and SCIE guidelines, as adapted and developed by Imogen Taylor et al. (2006) and Dixon-Woods et al. (2006), with a focus on the systematic review principles of rigour, comprehensive search strategies, and transparency in methods.

2.5.1 Search Strategy and Screening

To enhance validity (Barroso et al. 2003), avoid publication bias (Aveyard 2007) and ensure that 'user testimony' was identified (Rutter et al. 2010), a comprehensive search strategy was adopted. This involved the following methods:

- Searches of electronic bibliographic databases
- Searches of grey literature websites, internet search engines and the websites of relevant organisations
- Hand-searching of key journals and relevant organisations' publications
- Reference harvesting, citation tracking, author searching and personal contact with key authors, relevant professionals and practitioners, and visits to the Sense library.

Twelve electronic bibliographic databases were searched (see Table 1). These databases were chosen on the basis of recommendations in the SCIE guidelines (Rutter et al. 2010), other systematic reviews within social work (for example, Fisher et al. 2006, Imogen Taylor et al. 2006, Braye et al. 2011), results from the initial scoping searches and those which were available via Shibboleth or Athens passwords.

Table 1: Databases searched

Applied Social Sciences Index and Abstracts (ASSIA)
British Nursing Index (ProQuest)
Cumulative Index to Nursing and Allied Health Literature (CINAHL)
Education Resources Information Centre (ERIC)
International Bibliography of the Social Sciences (IBSS)
PsycINFO
Social Policy and Practice (via OVID)
PubMed
Social Services Abstracts
Sociological Abstracts
SCOPUS
Web of Knowledge (v.5.8)

Search terms were based on key concepts drawn from the review question and use was made of Boolean operators and search combinations (see Tables 2 and 3). Taylor et al. (2003) note that different authors may use a range of synonyms for the same concepts; this proved particularly so in relation to the terms used for ‘deafblindness’ (see Chapter One, section 1.2.1). Searching was therefore an iterative process, with terms being refined and developed. Searches were undertaken using both control terms (when available in the database) and free text. Where available in the database, the ‘search terms *anywhere*’ option was chosen, which Barroso et al. (2003) identify as a useful search technique.

Table 2: Search Terms Ageing With Deafblindness

Deafblind OR deaf-blind OR “dual sensory loss” or “dual sensory impair*’ OR ‘hearing and sight loss’ OR ‘hearing and sight impair*’ OR ‘hearing and visual loss’ OR ‘hearing and visual impair*’ OR ‘deafness and sight loss’ OR ‘deafness and sight impair*’ OR ‘deafness and visual loss’ OR ‘deafness and visual impair*’ OR ‘blindness and hearing loss’ OR ‘blindness and hearing impair*’ OR ‘vision and hearing difficulties’ OR ‘deafness and blindness’ OR ‘deafness and vision difficulties’ OR ‘sight and hearing difficulties’ OR ‘ usher syndrome’ OR ‘charge syndrome’ OR ‘congenital rubella syndrome’

AND

ageing OR aging OR old* OR senior* OR elder* OR aged OR “old age” OR gerontol*

Table 3: Search Terms Vulnerability and Deafblindness
Deafblind OR deaf-blind OR “dual sensory loss” or “dual sensory impair*’ OR ‘hearing and sight loss’ OR ‘hearing and sight impair*’ OR ‘hearing and visual loss’ OR ‘hearing and visual impair*’ OR ‘deafness and sight loss’ OR ‘deafness and sight impair*’ OR ‘deafness and visual loss’ OR ‘deafness and visual impair*’ OR ‘blindness and hearing loss’ OR ‘blindness and hearing impair*’ OR ‘vision and hearing difficulties’ OR ‘deafness and blindness’ OR ‘deafness and vision difficulties’ OR ‘sight and hearing difficulties’ OR ‘ usher syndrome’ OR ‘charge syndrome’ OR ‘congenital rubella syndrome’ AND vulnerab* OR maltreatment OR harm OR ‘adult protection’ OR abuse OR ‘at risk’ OR protect* OR safeguard*

Searching bibliographic databases alone is not sufficient, as highly relevant unpublished papers may be missed (Dixon-Woods et al. 2006, Rutter et al. 2010). To identify grey literature and relevant but unpublished material, Internet search engines and websites were used (see Tables 4 and 5). This included Amazon, which although a commercial website, is highlighted as useful for literature review searches (Bryman 2008): some material in this review (Stoffel 2012) was found solely on Amazon. Akin to other systematic reviews, I made an a priori decision to review only the first 100 hits on Google Scholar.

Table 4: Search engines and websites Ageing With Deafblindness

Internet Search Engines	Websites
BASE (Bielefeld Academic Search Engine Google Scholar JSTOR (Digital Library produced by ITHAKA) Open Grey Social Care Online (SCIE Database) Social Welfare at the British Library Portal SUMMON (Staffordshire University Search Tool)	Action on Elder Abuse Action on Hearing Loss Age UK Amazon Beth Johnson Foundation Brunel Institute for Ageing Studies Centre for Ageing Research, Lancaster Deafblind UK Department for Health Information Center for Acquired Deafblindness (Copenhagen) International Longevity Centre

	Joseph Rowntree Foundation Centre for Social Gerontology, Keele National Consortium on Deafblindness Royal National Institute for Blind People (RNIB) Sense Skills for Care Thomas Pocklington Trust

Table 5: Search Engines and Websites Vulnerability and Deafblindness

Internet Search Engines	**Websites**
BASE (Bielefeld Academic Search Engine Google Scholar JSTOR (Digital Library produced by ITHAKA) Open Grey Social Care Online (SCIE Database) Social Welfare at the British Library Portal SUMMON (Staffordshire University Search Tool)	Action on Elder Abuse Action on Hearing Loss Age UK Amazon Beth Johnson Foundation Brunel Institute for Ageing Studies Centre for Ageing Research, Lancaster Deafblind UK Department for Health Information Center for Acquired Deafblindness (Copenhagen) International Longevity Centre Joseph Rowntree Foundation Centre for Social Gerontology, Keele National Consortium on Deafblindness Royal National Institute for Blind People (RNIB) Sense Skills for Care Thomas Pocklington Trust

Deafblind Review (the publication of Deafblind International) and *Talking Sense* (publication of Sense) were hand searched. I also reviewed the *Deafblind Bibliography* (a list of sources constructed by UK based deafblind man James Gallagher, as part of his Deafblindness Web Resource) and *Selected readings on sensory loss in older age* produced by the Centre for Policy on Ageing Information Service. I visited the Sense Library and held discussions with Sense specialist practitioners. Finally, citation tracking, reference harvesting, author searching and personal contact with named authors enhanced the search.

Rutter et al. (2010:43) recommend having a 'clear cut-off time' within the searching strategy; the temptation to continue searching is strong, but prevents the review progressing. Nevertheless, Bryman (2008) maintains that a literature review should be an ongoing element of a research study, rather than being a discrete stage. Two tools were adopted to capture relevant material published subsequent to the searching: registration for email alerts via ZETOC (the British Library database), and, in recognition of the increased use of social media in research (Mollett et al. 2011) use of the hashtag '#deafblind' in a twitter account.

I adopted a three-stage screening process, focused predominantly on relevance. Certain references could be excluded on the basis of the title alone. Those references appearing relevant were stored in bibliographic software (EndNote vX6 Bld 8318) and the inclusion criteria (see section 2.5.2) applied following reading of the title and, where available, the abstract. Those appearing relevant were retrieved, read in full, and the inclusion criteria applied again. Details on identification, screening, eligibility and inclusion can be found in the PRISMA diagrams (Figure 2 and Figure 3) (PRISMA model from Moher et al. 2009).

2.5.2 Inclusion and Exclusion Criteria

The following criteria were adopted:

Table 6: Inclusion and exclusion criteria

Include references which:	**Exclude references which:**
• Relate to older deafblind people who have been deafblind for most of their lives. • Include the views and experiences of older deafblind people. • Are qualitative and quantitative studies,	• Relate only to those with single sensory impairment. • Relate only to deafblind children. • Relate only to those older people acquiring deafblindness in later life. • Lack clarity in relation to the deafblind

literature reviews, personal accounts and biographical material by deafblind people, health and social care practitioner authored materials and material produced by specialist organisations. • Are peer-reviewed and non-peer reviewed publications, conference proceedings, grey literature and material produced online; published and unpublished material. • Were produced from 1970 to date (1970 was the year deafblindness was first mentioned in a UK Act of Parliament). • Contain international and national material but only if available in the English Language.	population concerned. • Focus solely on medical treatments or medical interventions. • Were produced before 1970. • Are not available in the English language. • Cannot be retrieved in full.

For the second review question (vulnerability and deafblindness), the same criteria were largely adopted. However, following the initial scoping searches, which identified no material relating to the vulnerability of those ageing with deafblindness specifically, I decided to include material relating to any group within the deafblind population, including deafblind children and those with late-life acquired deafblindness.

I did not have sufficient resources to have material translated. Nevertheless, much of the material found stems from the USA or the Nordic Countries (Sweden, Norway, Iceland, Finland and Denmark) and was mostly available in English, having either been published in English in the first instance or already translated.

Figure 2: What is known about the experiences, views and key features of old age and ageing for deafblind people? (PRISMA)

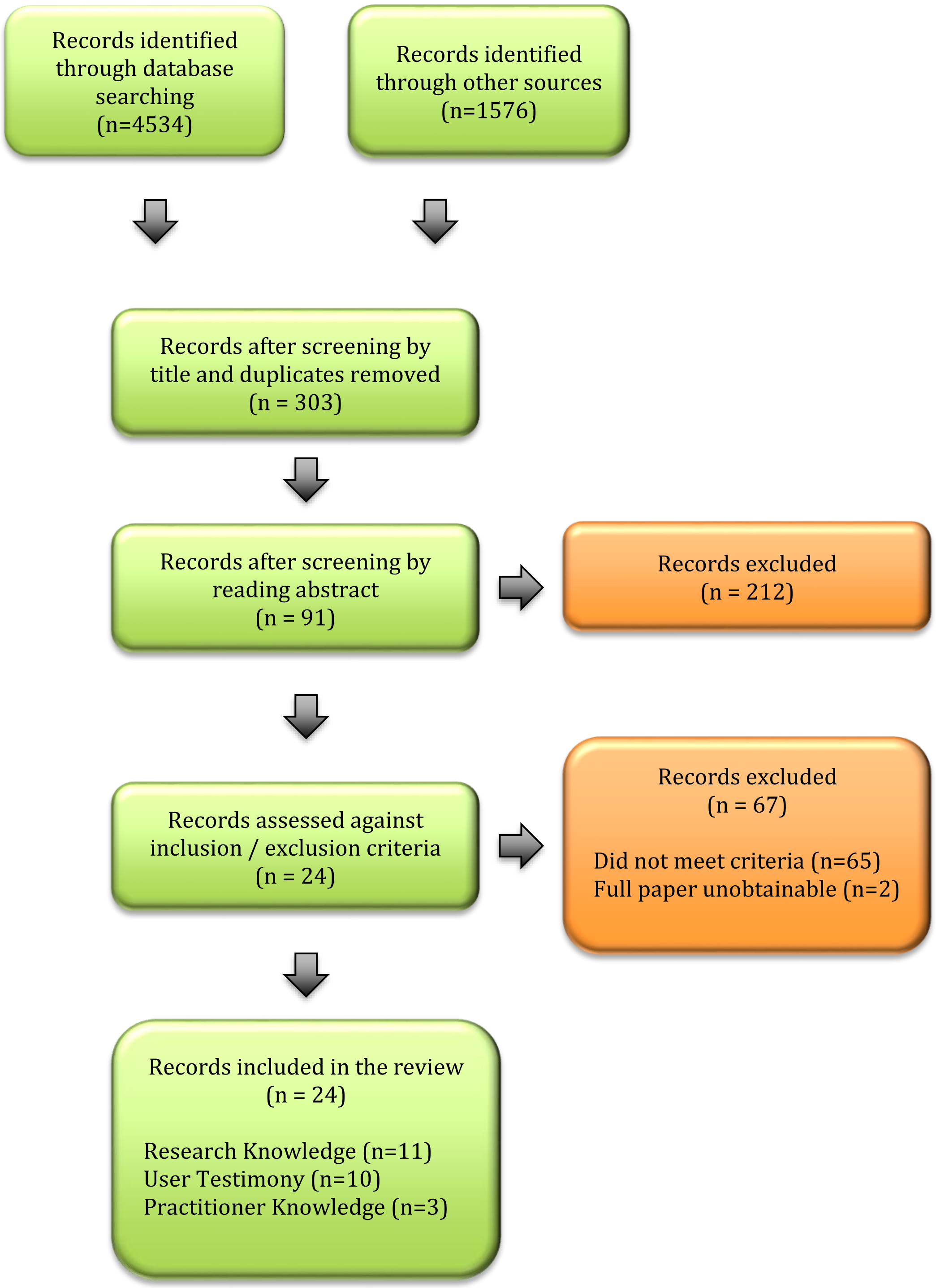
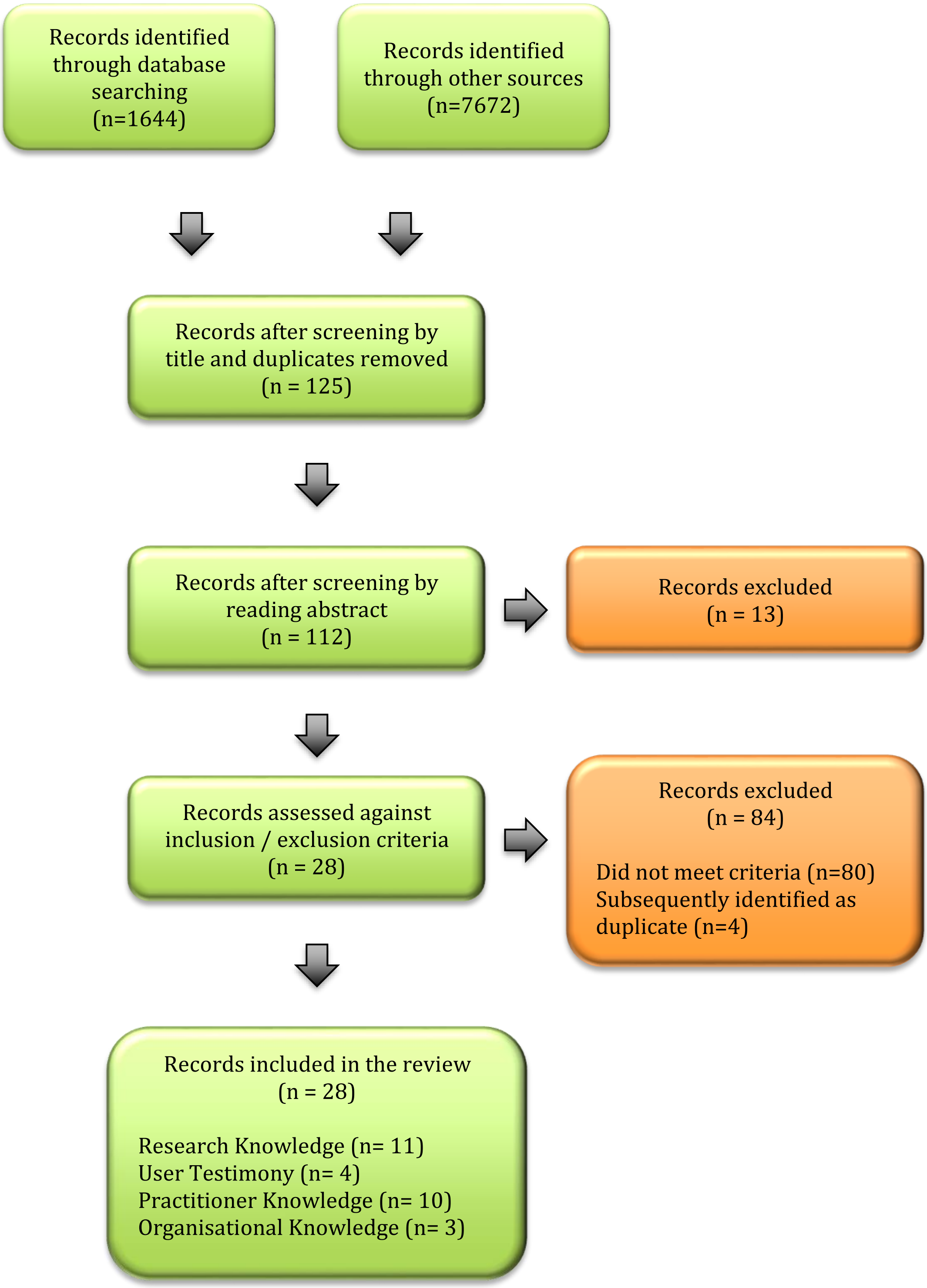


Figure 3: What is known about the vulnerability of deafblind people? (PRISMA)



2.5.3 Quality Appraisal

As explained in section 2.2.1, I adopted the TAPUPAS framework as a tool for quality appraisal. Although described as provisional, this standards framework can be used to appraise all types of social care knowledge, while recognising the value that all sources of knowledge have in contributing to the evidence base (Pawson et al. 2003). Use of the framework involves asking set questions of any type of knowledge (see Table 7) rather than acting as a replacement for quality judgement.

Table 7: TAPUPAS Framework

Domain	**Question**
Transparency	Is it open to scrutiny?
Accuracy	Is it well grounded?
Purposivity	Is it fit for purpose?
Utility	Is it fit for use?
Propriety	Is it legal and ethical?
Accessibility	Is it intelligible?
Specificity	Does it meet source–specific standards? The source specific standards are outlined in the SCIE '*Types and Quality of Knowledge in Social Care' Knowledge Review* (Pawson et al. 2003).

The limited number of topic relevant papers found resulted in priority being given to relevance over particular methodological standards (as suggested by Dixon-Woods et al. 2006). The low number of rigorous empirical studies included may be seen as a limitation of this review. Nevertheless, critique of the existing literature is offered within the synthesis, drawing on the principles of critical interpretive synthesis developed by Dixon-Woods et al. (2006).

2.5.4 Data Extraction and Synthesis

Data on the deafblind population concerned were extracted from the research knowledge, practitioner knowledge and user testimony. The provenance of information described in the practitioner knowledge was also identified: this was largely practice wisdom, professional experience, other literature or interviews with deafblind people. This information is recorded in Tables 8 and 9. I adopted an interpretative rather than aggregative approach to synthesis, owing to the nature of the review question and the significant diversity of material identified (Bryman 2008). This diversity of material, variety of reporting conventions, and the multiple definitions of deafblindness used, rendered standard thematic analysis as used in qualitative systematic reviews problematic. The approach therefore involved reading and re-reading the material selected in order to identify dominant themes, related concepts, similarities and incongruities (Fisher et al. 2006).

2.6 Experiences, Views and Key Features of Old age and Ageing for Deafblind People

2.6.1 Description of the Literature

A total of 24 references met the inclusion criteria (see Table 8). Eleven are primary studies, using various methods: in-depth and semi-structured interviews with deafblind people (Oleson and Jansbøl 2005, Göransson 2008, Kyle and Barnett 2012, Spring et al. 2012, Ellis and Hodges 2013b), interviews with deafblind people, their families and support workers (Yoken 1979), focus groups (LeJeune 2010, Gullacksen et al. 2011), and survey questionnaires (Laustrup 2004, Damen et al. 2005, Dammeyer 2010a). None of these studies focus specifically or solely on the experience of ageing with deafblindness; nonetheless, the topics and research questions of these studies were considered relevant to the review question: the experiences of deafblind people across the life course (Göransson 2008, Gullacksen et al. 2011); the experiences of being deafblind, including older deafblind people (Yoken 1979, Oleson and Jansbøl 2005, Kyle and Barnett 2012, Spring et al. 2012); analysis of the lives of people with Usher Syndrome, including some older people (Ellis and Hodges 2013b); challenges to independence for adults ageing with Usher Syndrome (Damen et al. 2005); and analysis of the late manifestations of congenital conditions (Laustrup

2004, Dammeyer 2010a). LeJeune's 2010 study is part of a larger research project entitled 'Persons Aging with Hearing and Vision Loss' (PAHVL Project). This title could be considered somewhat misleading: study participants had acquired a second sensory impairment after the age of 55 years, having previously been single sensory impaired. As such, although now 'ageing with deafblindness', they have not necessarily been deafblind for the majority of their lives. Nevertheless, the study was included, as the experiences of this population are distinct from those older people with late-life acquired deafblindness (LeJeune 2010).

Ten references are user testimony. These include collections of personal accounts of living with deafblindness (Duncan et al. 1988, Butler 2004b, Wolf 2006, Stoffel 2012) and personal accounts of living with deafblindness published as texts (Stiefel 1991), in specialist organisations' publications (Barr 1990, Bejsnap 2004, Pollington 2008) or in peer-reviewed journals (Gribs et al. 1995, Cohn 1998). Most accounts have been written by deafblind people themselves; others have been constructed in response to questions posed by friends and social care practitioners. Two references have a particular focus on the experiences of old age and ageing with deafblindness (Wolf 2006 and, Pollington 2008).

Three references are 'practitioner knowledge'. Two are by the same author and all three are written by social workers (Miner 1995, Miner 1997, Wickham 2011). These accounts draw on practice experience, but also draw on other literature and interviews with deafblind people. I do not classify them as research knowledge as information from the interviews is used for illustrative purposes, rather than subject to any clear data analysis. None of these accounts focus solely on the experiences of old age and ageing with deafblindness.

Table 8: Included Material on Ageing With Deafblindness				
Author(s) & Title	**Type of Knowledge**	**Description**	**Deafblind Population**	**Limitations**
Yoken (1979) *Living with Deafblindness: Nine Profiles*	Research Knowledge	Nine deafblind individuals (and their families and acquaintances) were interviewed by a Technical Service Specialist at Gallaudet College, Washington DC, United States of America (USA). The interview data and data from records are presented as nine profiles, with the aim that the deafblind individuals tell their own stories from which readers can draw meaningful conclusions. The profiles are presented in a book, published in the USA by The National Academy of Gallaudet College.	Nine deafblind adults, age range 23 to 71. Four of these are older adults who have been deafblind for the majority of their lives. Their ages are: 55, 64, 64 and 72. Some experiences of the husband of one of the nine individuals are also described. He is aged 77 and has also been deafblind for most of his life. The nine individuals have different family backgrounds and live in various regions of the US and in communities of various sizes.	The nine profiles draw on data from the deafblind participants, their families, records and 'the impressions of the interviewer / writer' (Yoken 1979: 6). It is not always clear in the profiles which data source is being used, and the text offers limited indication of how the 'impressions of the interviewer / writer' were formed. Deafblind people with recordable speech were recorded directly. Otherwise, the author (or the interpreter) spoke into the machine. Potentially, transcripts reflect

				only the interpreters' meaning and visual features of signed language are not recorded. There is limited ethnic and racial diversity – acknowledged by the author.
Laustrup (2004) *The ageing process and the late manifestation of conditions related to the cause of congenitally deafblind adults in Denmark*	Research Knowledge	Summary of research survey in Denmark, which collected information from 58 deafblind adults about the ageing process and late manifestations of congenital conditions. The complete report of the study is only available in Danish. This summary is published in the biannual Deafblind International Magazine.	58 congenitally deafblind adults. 26 with Congenital Rubella Syndrome (CRS) and 32 with other aetiologies (not recorded); 5 of the 32 non-CRS participants stated an unknown aetiology.	The complete report of the study is only available in Danish. This summary is published in the biannual Deafblind International Magazine, DbI Review. It is evident that the deafblindness of the participants is congenital; however, no current age of participants is given, just that they are aged '18 and over'. These details may be available in the full report.

Damen et al (2005) *The Usher lifestyle survey: maintaining independence: a multi-centre study*	Research Knowledge	European research study using a cross-sectional survey; data analysed using SPSS version 12.0. This survey was part of the CAUSE Project (an 18 month European Union project aimed at raising awareness of Usher Syndrome) and had a specific research question: Is it more difficult to remain independent while getting older, with regard to the type of Usher? Results and analysis are published in the international peer reviewed journal *International Journal of Rehabilitation Research.*	93 adults with Usher Syndrome (Usher Type I n=60; Usher Type II n=25; Usher Type III n=4; unknown Type n=4) from seven European Countries: France, Germany, Ireland, Italy, Spain, UK, and The Netherlands. 36.6per cent (n=34) of the participants were 'aged over 46'. In this paper, results of Usher Type I and II are presented.	No exact current age of participants is given: the very non-specific term 'older than 46' is used. The age categories of participants are described by the authors as arbitrary. It is not possible to determine from the paper the Type of Usher for those over 46. All participants are members of organisations of and for deafblind people Data from people with Usher Type III not presented.
Oleson & Jansbøl (2005) *Experiences from people with deafblindness – a Nordic Project*	Research Knowledge	A five-year Nordic research project aimed at the systematic collection of deafblind people's experiences. In-depth phenomenological interviews took place over a five-year period. Participants were interviewed six times. Analysis of the interview data is presented in six booklets, each with a different theme: theory and methods; receiving a diagnosis; getting	20 adults with Usher Syndrome from across the Nordic Countries (Norway-7; Sweden-6; Iceland-1; and Denmark-6).	The authors explicitly acknowledge the impact of the researcher and research itself on the phenomenon being studied. In particular

		support; being active; getting an education and work; narratives of everyday life.	Age range of Participants: 17-63 years old.	they note the potential implications of the pre-existing relationships between some of the deafblind participants and their interviewers; this includes the possibility that participants may have been reluctant to discuss certain topics with someone known to them in a professional capacity. Study involves multiple translation and interpretation; the authors do recognise the role of the interpreters as constructors of knowledge, and note that their presence in qualitative interviews may have affected the participants' responses.
Göransson (2008) *Deafblindness in a Life Perspective*	Research Knowledge	A four-year Swedish research project aimed at examining what life looks like for deafblind people in different age groups.	Deafblind people of all age groups and different types of	Participants recruited via specialist organisations of and

		The data were gathered from other research, eight in-depth qualitative interviews, eight interviews based on the World Health Organisation's International Classification of Functioning, Disability and Health, and two focus groups. The data were analysed using a life adjustment model and the research is presented in a book published by Swedish Publisher Mo Gårds Förlag.	deafblindness. Uses Nordic definition of deafblindness: " a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to such a degree that society is required to facilitate specific services, environmental alterations and/or technology" The two focus groups included: (a) Five people (3 men and 2 women), all working age, all using spoken language. (b) Thirteen parents of children and adolescents with deafblindness.	for deafblind people: potential for bias. Focus groups not organised for older people reducing data available for this group. When direct quotations from participants are used, information relating to age, age of onset and communication method of the participant is not always made explicit. Study involved multiple interpretation and translation activity.
Dammeyer (2010) *Interaction of Dual Sensory Loss, Cognitive Function, and*	Research Knowledge	A Danish study using a survey /questionnaire, building on the survey summarised by Laustrup (2004). The aim of the study was to investigate the relationship, if any, between communication abilities and cognitive function in congenitally deafblind adults. Data were	Data from 117 congenitally deafblind adults in Denmark. 22per cent of the	Questionnaires were completed by 'deafblind consultants' or care

Communication in People Who Are Congenitally Deaf-Blind		analysed with SPSS Version 17.0 The research is presented in the international peer-reviewed journal entitled *Journal of Visual Impairment & Blindness.*	participants were aged 50-59 years old; 7per cent were aged between 60-80 years old.	staff rather than deafblind people themselves. The title of the paper suggests a focus on congenital deafblind people, yet 3per cent of the participants have Usher Syndrome (whilst this is a congenital syndrome, the impairment of deafblindness is acquired).
LeJeune (2010) *Aging with a Dual Sensory Loss: Thoughts from Focus Groups*	Research knowledge	A USA based pilot study to inform the development of survey instruments for a larger research project: the Persons Aging with Hearing and Vision Loss (PAHVL Project). Data were gathered from focus groups, exploring issues related to persons ageing with both hearing and vision impairment. Research is published in an online journal published by the Association for Education and Rehabilitation of the Blind and Visually Impaired.	Older People ageing with hearing and vision loss. Focus on those with single sensory impairment, acquiring a second sensory impairment in later life. Nine Focus Groups, total of 68 participants.	Participants recruited via specialist organisations of and for deafblind people: potential for bias. In-depth analysis not undertaken. Demographic information not collected from all participants. No information on length of time between onset of first and second

			Seven focus groups concerned those who were visually impaired first and subsequently acquire a hearing impairment. Two focus groups concerned people who were deaf/hearing impaired first and subsequently acquired a sight loss. All but one participant aged over 55 (one was soon to be 55). The majority of participants over 62. All individuals self-identified as having dual sensory impairment. All participants were members of consumer or support groups. Further demographic information collected from 39 participants: 20per cent African American; 80per cent White American	impairment.

			64per cent women; 36per cent men 31per cent blind, 69per cent visually impaired; 26per cent Deaf American Sign Language Users; 74per cent Hearing impaired speech users. 3 participants had a cochlear implant. 2 participants were in paid employment.	
Gullacksen et al. (2011) *Life Adjustment and Combined Visual and Hearing Disability /Deafblindness – an Internal Process over Time*	Research Knowledge	A Swedish follow up study to Göransson (2008). The aim of this research was to use a life adjustment model to analyse the experiences of living with combined visual and hearing disability / deafblindness. The results and analysis of the research are published in an online text by the Nordic Centre for Welfare and Social Issues.	Focus on acquired deafblindness and the authors use the term deafblind as a generic word for "acquired combined visual and hearing disability, according to the Nordic definition of deafblindness" 15 participants in total; three focus groups: Swedish, Danish and Norwegian.	Participants recruited via specialist organisations of and for deafblind people: potential for bias. Age of participants given when direct quotations used, but not always age of onset. Interpreters used in data collection, but no acknowledgement that they are not neutral – lacks

			4 men and 11 women. Aged between 25-65; majority aged between 35-50. 11 were congenitally Deaf/Hearing impaired and subsequently acquired sight loss. 4 were visually impaired from birth or childhood, and subsequently acquired hearing impairment. All had progressive impairment; majority (n=11) had Usher Syndrome. 9 participants used spoken language (supported by hearing aids and assistive technology). 6 participants used sign language: 4 visual sign and 3 tactile sign. 1 participant had a cochlear implant. Swedish Focus Group: all women communicating with	exploration and acknowledgement. Difficult to cross-reference data on age, age of onset and communication preferences.

			sign language. Danish Focus Group: 3 women, 1 man, all communicating via spoken Danish. Norwegian Focus Group: equal number of men and women, using mix of communication methods.	
Kyle & Barnett (2012) *Deafblind Worlds*	Research Knowledge	A UK based research project, completed wholly in British Sign Language (and its deafblind variants). The aim of this study was to examine the experience of being Deafblind, to determine if this was similar to Deaf people's experience and to establish if Deaf and Deafblind people could work together. Qualitative data were gathered via interviews and group meetings. Interviewers were deafblind themselves. Quantitative data were also gathered on the characteristics of the participants. The research had not been formally published at the time of this review, but the full report was kindly retrieved directly from the first author.	21 participants. All used British Sign Language (and/or deafblind variants e.g. hands on or tactile sign language). Included congenitally deafblind people and people born Deaf, using British Sign language and identifying as a member of the Deaf community, subsequently acquiring a visual impairment. 85per cent of participants had	Age and age of onset of deafblindness not always made clear against participant direct quotations. Direct quotations presented in written English, but whole study completed in different modality (BSL).

			hearing loss before the age of 5 years old. 41per cent acquired sight loss by the age of 10 years old. 6 men and 15 women. Age Range: 21-66 years old. 41per cent aged 21-35 years old. Six of the participants were aged between 51-65 years old. 77per cent used visual BSL by preference.	
Spring et al (2012) *Deafblindness in Switzerland: Facing up to the facts. A Publication on the study "The living circumstances of deafblind people at different stages of their lives in Switzerland*	Research Knowledge	Empirical research study in Switzerland, using qualitative and quantitative methods, exploring the living circumstances of deafblind people registered with Swiss National Association of and for the Blind (SNAB) Centres. The study included semi-structured interviews with deafblind people. The research is published in Zurich by the Swiss National Association of and for the Blind.	35 deafblind people, 20 of whom were aged between 75 and 90.	The age of the participants is given, but not always the age of onset of deafblindness. When using direct quotations from participants or commenting on participants' views the authors do not always make clear the relevant age/age of onset details of the

				particular participant, albeit that such details of participants are detailed in the methods sections.
Ellis & Hodges (2013) *Usher Project Update – Interim Report.*	Research Knowledge	An interim report from an ongoing University of Birmingham, UK based study. At the time of the review, the study was yet to be completed. The aim of the research was to provide an insight into the lives of people with Usher Syndrome. This interim report was published online by the University of Birmingham, UK. N.B. Since completing this literature review, the final report has subsequently been published.	30 people with Usher syndrome from throughout the UK were interviewed. 12 participants were aged between 36-56.	The paper lacks detailed information on data analysis methods and interview protocols, and demographic information on participants is absent; however, this is an interim report on a research project that was ongoing at the time of writing. The oldest participant in the study is 56; the majority are younger adults.
Duncan et al (1988) *Usher's Syndrome. What is it, How to Cope, and How to Help.*	User Testimony	User testimony collated in the initial chapter of a textbook on Usher syndrome, published in the USA. The personal accounts are from individuals with Usher syndrome, who, according to the title of the chapter, were interviewed. Direct quotations from the individuals are presented under the following themed sub-titles: • Living well with Usher Syndrome • Feelings of Isolation and Rejection • Naming the Problem	Six individuals with Usher syndrome, two of whom are in their mid-forties: a man, aged 44 and a woman aged 46.	No inclusion of those older than 46. There is a clear focus on adolescence to middle age and the issues relevant to those at this life stage:

		- Coping with Usher Syndrome (in school and 'on the job' - Social and Recreational Activities - Satisfaction and Goals		diagnosis, education and schooling, work life. There is no clear information on how the six individuals were selected. Accounts based on personal experience. The two individuals in their 40s both work in sensory impairment services, a particular experience not representative of all deafblind people. The first language of the individuals is ASL, but direct quotations are presented in English.
Barr (1990) *Visiting the land of green ginger (with a little help from my friends).*	User Testimony	A personal account of living and ageing with deafblindness published in a UK based professional publication for those working with people with visual impairment entitled *New Beacon.*	The author was recorded as deafblind in 1966 and the account is published in 1990. She is over 70 years of age and describes having over	The exact age of the author is not made explicit. The account is based solely on personal experience.

			20 years of increasing blindness and 10 years of total deafness.	
Steifel (1991) *The Madness of Usher's. Coping with Vision and Hearing Loss (Usher Syndrome Type II.*	User Testimony	A personal account of living with Usher Type II written by an American woman, self-defined as ' now in her fifth decade of deafblindness'. The account is presented in book published by The Business of Living Publications, Texas, USA.	The author is a 60-year old American woman with Usher Type II.	The account is based on personal experience and the author has a particular background, not representative of all deafblind people, including a private education. The author has contact with organisations of and for deafblind people.
Gribs et al (1995) *A brief look at my life as a deaf-blind woman.*	User Testimony	A personal account of living with deafblindness, printed in the international peer-reviewed journal, *Journal of Visual Impairment & Blindness*. The author presents her account by responding to questions posed by the co-authors, one of whom is a rehabilitation worker and one of whom is a personal friend.	The account concerns an 87-year-old American woman who has been deafblind since her late teens.	The account is based solely on personal experience and limited in detail and depth.
Cohn (1998) *Problems experienced by hearing and visually impaired people*	User Testimony	A personal account of living with hearing and visual impairment published in peer-reviewed journal *British Journal of Visual Impairment.*	The author's current age is not explicitly defined, though it is possible to determine from content, that he	Exact age of the author not identified. The account is based on personal

			is now in later life. The author has experienced dual sensory impairment since his early teenage years and lives in England.	experience and the author has a particular background not representative of all deafblind people: he is a qualified physiotherapist.
Bejsnap (2004) *An account about being deafblind.*	User Testimony	A personal account of living with deafblindness published in a booklet accompanying a video aimed at promoting awareness of deafblindness in Denmark.	The author is a Danish man who has been deafblind since his teenage years. His current age is not made explicit, but he identifies as post retirement age.	Exact age of the author not identified. The account is based solely on personal experience; this experience includes having deafblind parents.
Butler (2004) *Usher 2: How is it for you?*	User Testimony	A collection of personal accounts / user testimony as shared with and recorded by a UK based charitable organisation for deafblind people. The accounts are published online by the charitable organisation Sense.	Five people with Usher Type II living in the UK. The ages of those sharing their experiences with the author are: 46, 50, 63 and 65. The age of the fifth person is not stated.	No contribution from the 'old old' with Usher Type II. Whilst the author interviewed the contributors to this piece, there is no information on the interview schedule and the piece presents as journalistic in style (reflecting its

				purpose). Direct quotations are included however. All the contributors are involved with the charitable organisation publishing the piece: one has worked for it in a paid capacity.
Wolf (2006) *A challenging time: older people's experiences of deafblindness*	User Testimony	Personal accounts from five older people with deafblindness living in the UK as reported to and published by a charitable organisation.	Five older deafblind people; two have acquired the impairment in later life (aged 92 and 78), two were born Deaf and have acquired sight loss in later life (described as 'early retirement age') and one has aged with deafblindness (aged 88; born profoundly Deaf and acquired increasing sight loss over a number of years).	Personal accounts with limited detail. All the contributors are involved with the charitable organisation publishing the piece. There is a clear focus in the publication on the importance and positive outcomes that can be achieved through support, much of which is provided by the charitable organisation publishing the work. Direct quotations are included, but for BSL

				users these are produced in English. Only one of the contributors has aged with deafblindness.
Pollington (2008) *Always change – the transitions experience by an older woman with declining sight and hearing.*	User Testimony	A personal account of living and ageing with deafblindness, published in charitable organisation's periodical. The author of this publication also contributed to the piece by Butler (2004).	The author is a 68-year-old English woman who has been deafblind since her teenage years as a result of Usher Type II.	Based solely on personal experience.
Stoffel (Ed) (2012) *Deafblind Reality. Living the Life.*	User Testimony	An edited text containing personal contributions from deafblind adults from various countries. The stated aim of the collection is to provide a 'genuine' understanding of the unspectacular but ongoing challenges of daily life for deafblind people. The editor himself is deafblind. The editor divides the text into separate topics: • Family Reaction and Support • Education (Primary and Secondary School) • Transition to Adulthood • Degeneration • 'Bad medicine' • Rehabilitation • Adult Education • Careers • Daily Life • Adult Relationships	12 deafblind adults from the following countries: USA n=9 England n=1 South Africa n=1 New Zealand n=1 Five of the 12 contributors are over 50 years old and have been deafblind for most of their lives: Age 52 (woman, England); Age 54 (man, USA); Age 53	Vague definition of deafblindness: 'a significant hearing loss and visual impairment' Greater focus on earlier to mid-life experiences and less attention on old age experiences. Only one contributor over 70. Author notes that some volunteers were recruited from an Internet group of

		- Communication - Cochlear Implants - Coping Contributors answer questions related to each of these topics. They were asked by the editor to share 'real experiences' rather than merely stating opinion.	(woman, USA); Age 71 (Woman, New Zealand); Age 57 (Woman, USA).	deafblind people. It is indicated that other recruitment methods were used, but these are not made explicit. Some contributors wrote their own 'articles' on the topics, whilst others just answered the questions posed and the editor expanded these into 'articles'. Whilst all material was sent to the contributors for proofreading and checking for accuracy, there is no indication in relation to which contributors wrote their own articles.
Miner (1995) *Psychosocial Implications of Usher Syndrome Type 1 throughout the Life Cycle.*	Practitioner Knowledge	A practitioner report drawing on practice experience, other literature, clinical vignettes and interviews with people with Usher Syndrome, Type 1. The author is a clinical social worker based in New York, USA at the time of publication, but now based in Los Angeles. The report is published in the international peer-reviewed journal, *Journal of Visual Impairment & Blindness.*	39 people with Usher Syndrome Type 1. The age of those interviewed ranged between 16-67 years old.	Two of the 39 participants in 1995 paper were known to the author personally. Such pre-existing relationships, particularly that between social worker and client, raises both

				methodological and ethical issues (Padgett 2008); these are largely unacknowledged and unexplored.
Miner (1997) *People with Usher Syndrome Type 2: Issues and Adaptations*	Practitioner Knowledge	A practitioner paper drawing on practice experience, other literature and interviews with adults with Usher Syndrome Type II over a four-year period. 32 people were interviewed by the author to illustrate the paper. The author is a clinical social worker based in New York, USA at the time of publication, but now based in Los Angeles. The paper is published in the international peer-reviewed journal, *Journal of Visual Impairment & Blindness.*	32 people with Usher Syndrome Type II. The age of some (not all) of the participants is given, and ranges between 24 and 45 years of age.	The demographic details of all the participants, including age, are not given. Nine of the 32 participants were clients or acquaintances of the author. The potential impact of this pre-existing relationship is not acknowledged or explored. The oldest participant was 45.
Wickham (2011) *Depression in the Deafblind Community: Working from a Social Work Perspective.*	Practitioner Knowledge	A practitioner paper drawing on practice experience and other literature to explore depression in the deafblind community, from a social work perspective. The author is a social worker for the Senses Foundation, Australia. The paper is published in the biannual publication of Deafblind	The author states that the paper is 'mainly related to adults with acquired deafblindness'. The paper considers	Limited detail on the literature drawn upon. Insufficient information provided in order to locate study referred to within the paper.

		International.	those with progressive or sudden dual sensory loss and refers to a study of those living with deafblindness over a period of time.	Refers to those with ‘acquired deafblindness’ but offers little further information in relation to age, age of onset and other characteristics.

2.6.2 Critical Interpretative Synthesis

2.6.2.1 Older people ageing with deafblindness: a hidden population

Wolf (2006:2) argues that older deafblind people are ‘often invisible and ignored’. While she is referring here to all older deafblind people, this review suggests that it is those older people who have aged with deafblindness that are most ‘invisible’. As noted, no studies focusing specifically and solely on the experiences of those ageing with deafblindness were identified. Although a distinction between those ageing with deafblindness and those acquiring the impairment in later life is made in the literature (Jansbøl 1999, Göransson 2008, Spring et al. 2012), the majority of research explores the experiences and needs of the latter group. Over 80 references relating to this population were identified during the database searches and an inherent assumption that ‘older deafblind people’ are those who have acquired the impairment in later life is apparent in the literature. Journal articles with titles such as ‘Vision and hearing loss in older adults’ (Berry et al. 2004), ‘Dual sensory impairment in an aging population’ (Saunders and Echt 2011), ‘Dual sensory impairment in older age’ (Schneider et al. 2011) and ‘An overview of dual sensory impairment in older adults’ (Saunders and Echt 2007) , *inter alia,* focus exclusively on those with late-life acquired deafblindness.; although this is made evident in the abstract or introduction of some material, in other work it is merely implied.

Papers such as those described above are excluded from this review. Nonetheless, included material also appears to marginalise the ‘ageing with deafblindness’ population. Larger scale studies, such as the five-year project by Oleson and Jansbøl (2005) and the survey-based study by Dammeyer (2010a) include very small numbers of those who have aged with deafblindness; just 7% of participants in the latter study (n=117) were aged over 60. In the Spring et al. (2012) study, 20 participants (n=35) interviewed were aged between 75 and 90; however, it is implied that most of these acquired deafblindness in later life. Furthermore, the studies’ oldest participants are often at an age considered to be the ‘young old’ (Moody and Sasser 2012). In five studies, the oldest participants range from 56 years old to 71 years old, with the majority being in their early to mid-sixties. One research study refers rather unspecifically to the oldest participants as being ‘over 46 years of age’, despite its stated focus on the difficulties in remaining independent for those with Usher Syndrome who are ‘getting older’ (Damen et al. 2005). The lack of inclusion of older people ageing with deafblindness may be linked to recruitment difficulties, rather than choice; Kyle and Barnett (2012:15) observe that it ‘proved more difficult to find older Deafblind people’ than younger deafblind people for their study.

Marginalisation of older people who have aged with deafblindness is also evident in material concerned with the ‘life course’ or ‘life cycle’. For example, Miner (1995) includes significantly less discussion on later life, than that on matters related to earlier life, such as infancy and childhood, adolescence, school experiences and early adulthood. The section on old age consists of just six very short paragraphs. Miner (1995:294) herself suggests that ‘much more work needs to be done on elderly people’s experiences with Usher syndrome’. The section titled ‘ageing with deafblindness’ in Göransson’s (2008) study is also shorter than those concerned with childhood and adolescence; while this section starts with the profile of an 81 year old woman who has aged with deafblindness, the majority of the chapter explores the experiences of those acquiring the impairment in later life. It is also noted in the study that older deafblind people were not included in the focus groups. The publication of the follow up study by Gullacksen et al. (2011) contains chapters on both childhood and adolescence, but no separate chapter on old age. The studies by Ellis and Hodges (2013b) and Oleson and Jansbøl (2005) seek to explore the experiences and lives of people with Usher Syndrome and deafblind people respectively. Although neither study adopts a life course perspective, in both studies the researchers clearly state a choice to focus on young deafblind people; no explicit reason is given for this decision.

Crow (2000:845) observes that Helen Keller ‘was a woman who lived to old age, yet is fixed in the public imagination as an eternal child’. Personal accounts of living with deafblindness often offer limited coverage of the experience of ageing. Both Coker (1995) and Murphy (1991) acquired deafblindness in childhood and are now in later life, yet in neither account do they report on nor describe their experience of getting older, choosing to focus on childhood, schooling and early adulthood; these accounts were therefore excluded from the review. Those personal accounts included, with the exception of Pollington (2008) and Wolf (2006), offer limited discussion in relation to getting older; most focus predominantly on earlier life experiences, particularly diagnosis, education, and adolescence.

2.6.2.2 Lack of clarity and methodological limitations

Neither a common deafblind population under study nor a shared definition of deafblindness was evident in the literature reviewed, mirroring Wittich and colleagues' (2013) systematic review; various definitions are used and differing groups of deafblind people included, making comparison across the material problematic. For example, while a functional definition, focusing on the implications of dual sensory impairment, is apparent in the majority of the material, there are subtle differences. Göransson (2008:22) and Oleson and Jansbøl (2005:17) adopt the common Nordic definition (see Chapter One, section 1.2.1) identifying deafblindness as 'a *severe* degree of combined visual and auditory impairment… [which] mutually reduces the prospect of using the potential residual vision or hearing' (my emphasis). Gullacksen et al. (2011) also adopt this definition in their follow up study. Dammeyer (2010a:720) similarly states the adoption of the agreed Nordic definition; however, the term 'severe' is dropped: 'a combined vision and hearing disability [that] limits activities of a person'. Yoken (1979:4) observes that all but one of her study participants 'fall into the standard, accepted description of deafblindness', yet she offers no clear explanation of this 'standard, accepted description', albeit that there is some reference to functional implications of the condition. Stoffel (2012:ix) makes no reference to functional limitations in his definition, referring instead to 'a significant hearing loss and visual impairment' and in his personal account, Cohn (1998:19) suggests a clear distinction between people with hearing and visual impairment and those who are 'truly deaf-blind'.

Some material focuses on adults whose deafblindness has a particular aetiology. For example, Duncan et al (1998), Steifel (1991), Miner (1995, 1997), Butler (2004), Damen et al. (2005), Pollington (2008), and Ellis and Hodges (2013) all focus on Usher syndrome. Although this work makes the focus explicit in the title or abstract, some does not: while the Oleson and Jansbøl (2005) study is entitled '*Experiences from People with Deafblindness*', all the participants involved had Usher syndrome. Other material narrows the deafblind population being considered by focusing on either congenital deafblindness (see, for example, Laustrup 2004 and Dammeyer 2010) or acquired deafblindness (see, for example, Gullacksen et al. 2011 and Wickham 2011), or by focusing on those using particular communication methods (Kyle and Barnett 2012). Being explicit about the population concerned recognises the heterogeneity of the deafblind population; nevertheless, awareness of differences between these groups must be acknowledged when reporting common themes across the literature.

As noted, researchers highlight significant differences between the needs and experiences of those acquiring deafblindness in later life, and those who have aged with the condition. Nonetheless, there is often a lack of clarity in the literature, in relation to age of onset of deafblindness and current age, making it impossible to determine to which of these populations the research participants belong. For example, in both the Gullacksen et al. (2011) and Spring et al. (2012) studies, the participants' age is recorded, but not always the age of onset of deafblindness. Laustrup (2004) and Damen et al. (2005) make it apparent whether the participants' deafblindness is congenital or acquired in adolescence; however, no current age of participants is given by Laustrup (2004), just that they are aged '18 and over' and Damen et al. (2005) use the nebulous phrase 'older than 46'. Furthermore, in studies that include participants across age groups, authors using direct quotations from participants or commenting on participants' views do not always make clear the age and age of onset details of the particular participant, albeit that such details are recorded in the methods sections. This lack of detail is particularly evident in the Kyle and Barnett (2012) and Spring et al. (2012) studies. Yoken's (1979:6) nine profiles draw on data from the deafblind participants, their families, records and 'the impressions of the interviewer / writer'. It is not always clear in the profiles which data source is being used, and the text offers limited indication about how the 'impressions of the interviewer / writer' were formed.

Methodological limitations are evident in the research material; in the majority of studies these are recognised by the authors. For example, LeJeune (2010) acknowledges that in-depth analysis of focus group data was not undertaken, and that demographic information was not collected from all participants. Ellis and Hodges' (2013) paper lacks detailed information on data analysis methods and interview protocols, and demographic information on participants is absent; however, this is an interim report on a research project that was ongoing at the time of writing. Oleson and Jansbøl (2005) explicitly acknowledge the impact of the researcher and research itself on the phenomenon being studied. In particular they note the potential implications of the pre-existing relationships between some of the participants and their interviewers; this includes the possibility that participants may have been reluctant to discuss certain topics with someone known to them in a professional capacity. Such an impact is not always acknowledged or explored in the practitioner authored papers. For example, nine participants (n=32) interviewed for Miner's (1997) paper were either her clients or acquaintances, and two participants (n=39) in her earlier paper were known to her personally. Such pre-existing relationships, particularly those between social workers and clients, raise both methodological and ethical issues (Padgett 2008); these are largely unacknowledged and unexplored in both papers.

The use of interpreters and translation in research also poses epistemological, methodological and practical challenges (Temple and Young 2004, Regmi et al. 2010, Berman and Tyyskä 2011). As deafblind people use a range of languages and methods of communication, both expressively and receptively (Barnett 2002, Heine and Browning 2004, Hart 2008, Hersh 2013a), much research involving deafblind people, including most of that included in this review, involves interpretation and translation. Some included studies involve multiple translations, not only from Sign Languages to English, but also from a range of European languages (for example, Norwegian, Swedish, and Danish) to English (Oleson and Jansbøl 2005, Göransson 2008, Gullacksen et al. 2011, Spring et al. 2012). Nevertheless, the challenges associated with such involvement are not always considered or addressed.

Regmi et al. (2010) highlight the risk of interpreters omitting information from participants that they deem unimportant. 'Back translation', the process of translating translated material back into the original language, without referring to the original material, in order to check accuracy, is therefore suggested as a strategy to ensure accuracy and reliability (*ibid.*). Ostensibly, this process is not adopted in any studies in this review. However, Temple and Young (2004) argue that 'back translation' is not always effective where the languages use different modalities, as in the case of English and Sign Languages. Writing specifically about research with British Sign Language users, Temple and Young (2004) stress the epistemological challenges of interpreter and translation use. They contend that users of different languages may construct different views of the social world, which presents a challenge to the researcher in accurately representing participants' experiences in a different language (*ibid.*). Many research participants in studies included in this review use sign languages (received visually or tactually) yet direct quotations are always represented in written English, arguably rendering the source language invisible. Furthermore, Temple (2002) maintains that interpreters are not neutral but are themselves constructors of knowledge in the interpreting act. While some studies record the use of interpreters (Yoken 1979, LeJeune 2010, Gullacksen et al. 2011, Spring et al. 2012), Oleson and Jansbøl (2005) are the only authors to recognise their role as constructors of knowledge, noting that their presence in qualitative interviews may affect the participants' responses. Further detail on the methodological and practical challenges associated with the involvement of interpreters and translation in qualitative research and my own approach to managing these challenges is described in Chapters Four and Five.

Kyle and Barnett (2012) contend that knowledge of deafblind people's experiences can be gained through their autobiographical work. Gullacksen et al. (2011:18-20) agree, noting that:

> these personal stories relay important knowledge… [and that the] most important source of knowledge when it comes to understanding …. how people cope with a life with deafblindness, are the people who actually experience it.

Nevertheless, many personal accounts are limited in detail and depth, offering only a 'snapshot' of life experiences. Moreover, such accounts cannot be considered representative of the experiences of all deafblind people. Those writing or contributing to these accounts have their own particular backgrounds, which undoubtedly impact on their experiences; this includes, *inter alia*, having a private education (Stiefel 1991), having deafblind parents (Bejsnap 2004) and being a qualified physiotherapist (Cohn 1998). The majority of those contributing to the personal accounts also have some contact with organisations of and for deafblind people. This contact is the main method of participant recruitment in the majority of the research studies (Yoken 1979, Damen et al. 2005, Oleson and Jansbøl 2005, Göransson 2008, LeJeune 2010, Gullacksen et al. 2011, Spring et al. 2012, Ellis and Hodges 2013b). The potential for bias that this engenders should be acknowledged (Padgett 2008).

Despite the near invisibility of older people ageing with deafblindness in the literature, and the methodological limitations as described, common themes relating to their experiences were evident across the material reviewed. These themes, considered next, were: ongoing change and adjustment; reciprocal impact; maintained and threatened independence; and relationships with social care services.

2.6.2.3 Ageing with deafblindness: ongoing change and adjustment

Although sensory impairments have been described as 'stable' conditions (Shakespeare and Watson 2001, Kelley-Moore 2010), such description appears contrary to the experiences of those ageing with deafblindness. The concept of change, in both the impairment and its impact as people age, is prevalent across the literature. Ellis and Hodges (2013) and Spring et al. (2012) identify change as a specific and common theme emerging from their interview data, and Göransson (2008:16) concludes that 'deafblindness can never be regarded as something static'. Changes in the impairment as people age are discussed by Miner (1995, 1997), in both her papers, and by those ageing with deafblindness in the personal accounts presented by Butler (2004), Wolf (2006) and Stoffel (2013). The experience of change also forms the central theme of Pollington's (2008) personal account.

Changes in vision and hearing are a particular experience. Wolf (2006:24) observes that even those 'who may have been [deafblind] for many years, see a worsening of their condition'. Older deafblind people report deterioration in both their hearing and vision in much of the material (Yoken 1979, Duncan et al. 1988, Stiefel 1991, Oleson and Jansbøl 2005, Göransson 2008, Pollington 2008, LeJeune 2010, Gullacksen et al. 2011, Spring et al. 2012, Stoffel 2012), with changes in vision in particular for those with Usher syndrome, owing to the nature of retinitis pigmentosa (RP) (Duncan et al. 1988, Stiefel 1991, Miner 1995, Miner 1997, Butler 2004b, Damen et al. 2005, Stoffel 2012, Ellis and Hodges 2013b). Laustrup (2004) identifies that some of these changes result from the original cause of deafblindness and potential late manifestations of these aetiologies; others are attributed to other conditions, often age-related. Barr (1990) describes the experience of both. Laustrup (2004) also highlights that progressive impairment of vision and hearing is not limited to those ageing with acquired deafblindness, but also those with congenital deafblindness. This challenges the perception of congenital sensory impairment as 'stable' or 'static' and Göransson's (2008) suggestion that for those ageing with congenital deafblindness the core challenge is external changes throughout the life course, rather than changes in hearing and vision. The nature and timing of hearing and vision deterioration are variable. Participants in Göransson's (2008) and Spring et al's. (2012) studies and contributors to Stoffel's (2012) collection of personal accounts report variation and periods of stability and fluctuation; two older deafblind participants in the Oleson and Jansbøl (2005:14) study discuss changes in vision having no 'fixed pattern'. Changes in hearing and vision are not restricted to deterioration; some experience improvements as a result of either changes in their condition or medical intervention (Yoken 1979, Stoffel 2012).

As a consequence of changes in vision and hearing, those ageing with deafblindness often describe their need to make adjustments. Individual adjustment is a concept common across much of the practitioner knowledge, user testimony and research studies, particularly adjustment to loss. Miner (1995:287) states that 'Usher syndrome…. requires multiple adaptations throughout the life cycle' and her later paper on Usher Type II focuses specifically on adaptations (Miner 1997). Adjustment is not a one-off event. Yoken (1979), Stiefel (1991), Göransson (2008), Gullacksen et al (2011) and Wickham (2011) all report repeated and ongoing adjustment. A contributor to Duncan et al's (1998) collection of personal accounts refers to 'a constant adjustment' as she ages with Usher syndrome. Those ageing with deafblindness make a range of adjustments: psychosocial adaptation and emotional acceptance of deteriorating senses; changes in relationships, including personal relationships and relationships with social care services; and learning new ways to complete activities of daily living, use modern assistive technologies and access information (Duncan et al. 1988, Gribs et al. 1995, Miner 1995, Miner 1997, Oleson and Jansbøl 2005, Göransson 2008, Gullacksen et al. 2011, Stoffel 2012, Ellis and Hodges 2013b).

A particularly common adjustment experience for those ageing with deafblindness concerns communication and communication method. Participants in a number of studies, practitioners and those offering personal accounts describe how changes in hearing and vision render existing communication methods unsatisfactory, making communication difficult (Miner 1997, Damen et al. 2005, Oleson and Jansbøl 2005, Göransson 2008, Gullacksen et al. 2011, Spring et al. 2012, Stoffel 2012); Cohn (1998) notes that deterioration in either hearing or vision can affect communication ability, and argues that it can be difficult to determine which is having the most significant impact. Many older deafblind people describe how they have needed to learn new methods of communication over their life course (Göransson 2008, Gullacksen et al. 2011, Spring et al. 2012). For example, an 89 year old participant in Göransson's (2008) study, Deaf from birth and visually impaired from early childhood, describes her adjustment to receiving sign language tactually, having previously received it visually. In another account, a 57 year old woman deafblind from childhood, contributing to Stoffel's (2012) collection, describes a number of adjustments, moving from oral communication and lip-reading, to sign language, to tactual methods, and then returning to oral communication supported by cochlear implants.

2.6.2.4 Ageing with deafblindness: reciprocal impact

In her personal account, Pollington (2008:32) states that she 'cannot divorce ageing from deafblindness because that is what I am'. The relationship between ageing and deafblindness and the reciprocal impact they have are recurring themes across the literature. Gullacksen et al. (2011) observe that adjustment to deafblindness is a process that occurs alongside the ageing process: changes related to ageing occur concurrently with changes in the impairment. Brennan and Bally (2007) highlight that for many older people acquiring deafblindness in later life, the effects of age-related conditions exacerbate the impairment and *vice versa*. It appears that some adults ageing with deafblindness also experience this reciprocal exacerbation. Stiefel (1991) and those offering personal accounts reported by Wolf (2006) and Stoffel (2012) include descriptions of a combination of age-related conditions and deafblindness adversely impacting on mobility, communication and activities of daily living. The impact of this exacerbation is captured in the words of a 71-year-old woman, deafblind from adolescence:

> I have spent most of my adult life living alone with increasing disabilities.... Now that I'm of retirement age, the difficulties are closing in (Contributor in Stoffel 2012:201-2).

Age-related conditions, or late manifestations of the original aetiology of deafblindness as people age, result not only in increased physical, neurophysiological and cognitive impairment (Laustrup 2004, Dammeyer 2010), but may also affect previously used strategies. For example, a 77-year-old participant in Yoken's (1979) study describes how loss of sensitivity in his fingers as he has aged, has resulted in braille (a method previously used to access information) no longer being accessible. Stiefel (1991) experiences such increased impairment and wider effects as 'accelerated' ageing. Laustrup (2004) similarly observes incidences of what he terms 'early' or 'premature' ageing in data collected on the ageing process of congenitally deafblind adults.

It is not just age-related physical changes that exacerbate the challenges of deafblindness. Göransson (2008) and Wickham (2011) argue that living with deafblindness over a long period of time, combined with environmental changes, impacts on older deafblind people's experiences. Events over the life course can be experienced with a sense of uncertainty or difficulty when one has had a life of reduced access to information, communication difficulty and high levels of isolation (Gullacksen et al. 2011, Wickham, 2011). Grandparenthood, a role associated with old age (Green 2010), is reported as challenging by a woman ageing with Usher Syndrome Type I:

> I can never be just a regular grandmother. Grandmothers can help their daughters and keep babies in their houses overnight alone. I can never do that (Deafblind woman aged 55 in Miner, 1995:6).

Changes in social networks and loss of friends, particularly those competent in deafblind communication methods, are described as challenging by deafblind people as they age (Yoken 1979, Gribs et al. 1995, Göransson 2008, Stoffel 2012). Such changes and loss can be the result of age-related difficulties facing the friends themselves, bereavement or geographical distance. People with Usher syndrome report particular difficulties in maintaining links with the Deaf community, as they age and their vision deteriorates (Miner 1995, Kyle and Barnett 2012). Kyle and Barnett (2012:13) found that:

> their position in the Deaf community is weakened as their sight declines and they are often to be found only in the margins of society, and then *as elderly people, may disappear off the radar altogether* (my emphasis).

Notwithstanding these experiences, the relationship between ageing and deafblindness is not always perceived as negative. Pollington (2008) describes the potential for her to be 'forever young' as she cannot see the physical effects of ageing, such as changing hair colour and wrinkling skin. She also describes becoming increasingly similar to her generational peers, as they acquire age-related sensory impairments: rather than standing out as a person with impairment, she describes ‘merg[ing] into the background’ (*ibid.:*33).

2.6.2.5 Independence: maintained or threatened

Although Pollington (2008) and participants and contributors in Yoken (1979), Oleson and Jansbøl (2005), Spring et al (2012) and Stoffel (2012) describe declining independence and concerns about threats to independence as they age, many participants in Kyle and Barnett’s (2012) study define themselves as independent; however, the authors do acknowledge differing understandings of independence. For some older deafblind people, living with the condition for a long time has facilitated easier adjustments, enabled them to maintain their independence and become increasingly self-reliant (Yoken 1979, Göransson 2008, LeJeune 2010, Stoffel 2012). For example, participants in Göransson’s (2008) research explain how they learn to manage deafblindness by drawing on earlier adjustment experiences. Participants in LeJeune’s (2010) focus groups, particularly those who lived with hearing loss before acquiring sight loss, describe how earlier experiences prepared them for future challenges and Stiefel (1991) discusses various techniques she has learned over time which enable her to manage the impact of Usher syndrome. Yoken (1979) observes that for two of her participants who have lived with deafblindness for the majority of their lives, the condition is considered no more than a human characteristic comparable to sex, age or race. This perception is mirrored in the words of a 54-year-old man, deafblind from the age of eight:

> The hearing and vision losses have been with me so long that I have practically taken them as they have come… My vision and hearing losses are not a big deal (Contributor; in Stoffel 2012:88-9).

Similarly, Bejsnap (2004), deafblind since adolescence, describes almost forgetting that he is deafblind, now that he is in later life.

In contrast to these experiences, for some older people, living with deafblindness for a long time does not make maintaining independence or coping easier. Damen et al. (2005) report that people with Usher syndrome, particularly Type I, had increased difficulties maintaining their independence as they aged. Stiefel

(1991) uses the metaphor of madness in her personal account of the challenges of living and ageing with Usher syndrome and there is evidence in her narrative that living with deafblindness for a long time does not make things easier:

> The problems and difficulties never go away, never get easier, and never seem resolvable (*ibid.:*49).
>
> Usher syndrome causes far more problems over the years…. It does not get better. You will not reach a permanent plateau in adjustment (*ibid.:*57).
>
> The difficulties I have mentioned…. never cease (*ibid.:*64).

Comparably, a 55-year old woman with Usher syndrome Type II cited in Butler's (2004) paper suggests that life gets harder each year, not easier. As described by participants in Göransson's (2008) study, just as one adjusts and 'gets used to' deafblindness, then vision and/or hearing deteriorate further and one is faced with the need to adjust again.

As a result of these challenges and age-related changes, a deafblind person's independence can be threatened, as they get older. Nevertheless, not all deafblind people state a desire to be independent. Barr (1990:336) explicitly expresses a dislike of the concept, stating that she is 'always grateful for a helping hand'; she adds that it is her 'freedom' rather than independence that she values. This 'helping hand' may come from family, friends, other informal carers or formal social care services.

2.6.2.6 Relationship with social care services

Those with late-life acquired dual sensory loss rarely consider themselves deafblind (Göransson 2008, Pavey et al. 2009); therefore, they do not always make contact with, nor get referred to, specialist social care services (Horowitz 2003, Roberts et al. 2007, Sense 2009). In contrast, older people who have aged with deafblindness express a desire to continue to engage in further training and rehabilitation services, even in later life (Duncan et al. 1988, Barr 1990, Pollington 2008, Stoffel 2012). This includes learning how to use new assistive technologies (Stoffel 2012), using new mainstream technologies (Stoffel 2012), and engaging in rehabilitation services, such as learning braille and mobility training (Gribs et al. 1995, Pollington 2008, Stoffel 2012). At the age of 70, Barr (1990) describes starting a course at a Further Education College and 87-year-old Helen Gribs, deafblind from late adolescence, explains that she entered a rehabilitation programme when in her 70s and began attending American Association of Deaf-Blind Persons' conventions aged 73 (Gribs et al. 1995).

While there are accounts of positive engagement with deafblind social care services in later life, some older deafblind people express concern about the ability of deafblind services to meet their needs as older people (Gribs et al. 1995, Cohn 1998, Göransson 2008) and mainstream older people's services to meet their needs as deafblind people (Göransson 2008, Spring et al. 2012, Stoffel 2012). For example, an 89-year-old woman, deafblind since early adulthood, describes feeling 'too old' to attend organised social activities for deafblind people (Göransson 2008). She goes on to describe how the staff from the older people's home care and day care services she uses cannot communicate with her. Barr (1990) describes feeling excluded from older people's services and although not yet experiencing such exclusion, a 71-year-old contributor in Stoffel's (2012:232) collection expresses a fear that mainstream services will not meet her needs in the future, leaving her to experience 'isolation [that] will be horrific'. Miner (1995) highlights that those ageing with Usher syndrome are not always even aware of the ageing process nor services for older people, owing to a life of reduced access to information.

Those who have aged with deafblindness now living in mainstream older people's residential settings (for example retirement villages and care homes) describe particular experiences of isolation and unmet need (Göransson 2008, Spring et al. 2012, Stoffel 2012). The isolation is not only a consequence of staff lacking necessary communication skills, but also a result of being the only deafblind person in the setting. A contributor in Stoffel (2012:93) explains that her co-residents are 'elderly and can't be bothered with writing notes to communicate with [her]' and Helen Gribs describes how being the only deafblind person living in her setting has left her feeling 'lonesome' (Gribs et al. 1995:209).

Advances in assistive technology for deafblind people are also not always considered positive for those ageing with the condition. For example, older participants in Göransson's (2008) research report having difficulties with assistive technology owing to changes in their fine motor skills. Cohn (1998) describes having difficulties with changing technologies, including modern, and invariably smaller, hearing aids. Helen Gribs is also described as disliking her newer telecommunications equipment, compared to the equipment used earlier in her life that 'she loved for so many years' (Gribs et al. 1995:197).

2.7 The Vulnerability of Deafblind People

2.7.1 Description of the Literature

A total of 28 references met the inclusion criteria (see Table 9), eight of which were also included in the first part of this review. Eleven are research knowledge, using a variety of methodologies, methods and approaches: literature reviews (Marks 1998, Danermark and Möller 2008); qualitative semi-structured interviews, both individual and group (Heine and Browning 2004, Göransson 2008, Kyle and Barnett 2012, Hersh 2013a); focus groups (LeJeune 2010, Gullacksen et al. 2011); case studies and analyses of pre-existing datasets (Pavey et al. 2009); and structured questionnaires and surveys subject to quantitative analysis (Bodsworth et al. 2011, Viljanen et al. 2012). None focus specifically or solely on the experience of vulnerability among deafblind people; nevertheless, the topics explored were considered relevant to the review question: learned helplessness (Marks 1998); ontological security (Danermark and Möller 2008); psychological distress (Bodsworth et al. 2011) and fear of falling (Viljanen et al. 2012). Furthermore, participants in four of the studies discuss and describe experiences of feeling vulnerable (Heine and Browning 2004, Göransson 2008, Pavey et al. 2009, LeJeune 2010); in three studies, vulnerability is emphasized as a key theme emerging from the data (Gullacksen et al. 2011, Kyle and Barnett 2012, Hersh 2013).

Four references are user testimony; this includes two accounts by deafblind people included in the first part of the review (Stiefel 1991, Pollington 2008).

Deafblind people also write the other two. Neither focus specifically on vulnerability, but both include descriptions of experiences of fear, insecurity and feeling vulnerable. In a paper published in *The Lancet,* Henderson (2000) describes how she copes with Usher Syndrome Type I. In a more informally presented personal account, published online by Sense, Steve (Surname not identified) (2012), a deafblind man with Alström Syndrome, reflects on his experiences and thoughts about adult social care. The author of this latter account maintains anonymity, using only his first name.

Ten references are practitioner knowledge; two of these are included in the first part of the review (Miner 1997, Wickham 2011). The material is written by professionals and practitioners from a range of disciplines: specialist education (Moss and Blaha 2001, Smith 1993); developmental and specialist psychology (Mar 1993, Volden and Saltnes 2010); psychiatry (Volden and Saltnes 2010); social work (Luey 1994, Miner 1997, Wickham 2011); domestic violence services (Merkin and Smith 1995); and orientation and mobility instruction (Sauerburger 1993). It draws predominantly on the authors' practice experience, but also cites other literature and interviews with colleagues in the field, deafblind people and their families. None focus solely on vulnerability among deafblind people, though one includes a chapter on vulnerability to sexual abuse (Moss and Blaha 2001). However, all include consideration of vulnerability, in the context of service development and unmet need (Mar 1993, Sauerburger 1993, Smith 1993, Luey 1994, Merkin and Smith 1995, Volden and Saltnes 2010), adaptation to progressive impairment (Miner 1997), professional and personal relationships (Butler 2009) and the risk of depression (Wickham 2011).

Three references are organisational knowledge. All are produced and published, or presented, by the two major UK charities for deafblind people: two by Sense (Kiekopf 2007, Sense 2012) and one by Deafblind UK (Deafblind UK 2007). Two draw on organisational survey data to report on deafblind people's experiences of NHS health care (Deafblind UK 2007) and social care (Sense 2012). The third, a paper presented at an international conference, specifically explores vulnerability among deafblind people, contextualising the discussion by drawing on data from the organisation's 'abuse database' (Kiekopf 2007).

Table 9: Included Material on Vulnerability and Deafblindness				
Author(s) & Title	**Type of Knowledge**	**Description**	**Deafblind Population Concerned**	**Limitations**
Marks (1998) *Understanding and Preventing Learned Helplessness in Children who are Congenitally Deaf-blind.*	Research Knowledge	A literature review linking the literature on learned helplessness with that on best practices in teaching deafblind children. The paper's aim is to explore how practitioners in education and care can prevent or reduce learned helplessness in deafblind children. In addition to drawing on the literature, the author, a deafblind specialist from the Department of Special Education, Michigan State University, East Lansing, also draws on her own experience teaching and consulting in the field. The paper is published in the international peer-reviewed journal, *Journal of Visual Impairment & Blindness.*	Congenitally Deafblind Children	No information on how literature reviewed was found, selected or appraised. Literature used related to 'best practice'; no indication in the paper detailing how these best practices have been validated or identified.
Heine & Browning (2004) *The communication and psychosocial perceptions of older adults with sensory loss: a qualitative study.*	Research Knowledge	An Australian qualitative research study exploring the communication and psychosocial perceptions of older adults with single or dual sensory loss, acquired in later life. Research participants were all known to the Vision Australia Foundation (a not for profit organisation providing services to visually impaired people).	Older Adults (all aged over 60) with single or dual sensory loss, acquired in later life (n=10; 4 with dual sensory loss: 1 man and 3 women). All legally blind (Snellen 6/60 or worse).	No further details on age or age of onset of deafblindness for participants Participants recruited via specialist organisations of and for deafblind people: potential for bias.

		Data were gathered from individual and group interviews. The interviews were recorded (video or audio) and transcribed verbatim. Data were analysed using content and thematic analysis, with a focus on participants' meanings, motives, feelings and ideas. Feelings of anxiety and fear were evident in the data. The research is published in the international, interdisciplinary and peer-reviewed journal *Ageing and Society.*	All speech users.	
Danermark & Möller (2008) *Deafblindness, Ontological Security and Social Recognition.*	Research Knowledge	A discussion paper, which explores deafblindness in relation to trust, ontological security, social recognition and self-identity. The paper draws on the literature related to ontological security and research with deafblind people to explore how the deafblind population experiences the phenomenon. Both authors are from the Swedish Institute for Disability Research, Orebro University, Sweden. The paper is published in the peer-reviewed *International Journal of Audiology* (a merger of three former journals: *Audiology, British Journal of Audiology* and *Scandinavian Audiology*).	Specific focus on adults with acquired deafblindness, excluding older people acquiring deafblindness in later life. Authors note that people with acquired deafblindness are 'a very heterogeneous group'.	No information on how the literature reviewed was found, selected and appraised.
Göransson (2008) *Deafblindness in a Life Perspective*	Research Knowledge	A four-year Swedish research project aimed at examining what life looks like for deafblind people in different age groups.	Reports on deafblind people of all age groups and different types of deafblindness. Authors acknowledge the	Participants recruited via specialist organisations of and for deafblind people: potential for bias.

		The data were gathered from other research, eight in-depth qualitative interviews, eight interviews based on the World Health Organisation's International Classification of Functioning, Disability and Health, and two focus groups. Experiences and issues related to vulnerability are evident in the data. The data were analysed using a life adjustment model and the research is presented in a book published by Swedish Publisher Mo Gårds Förlag.	differences between congenital and acquired deafblindness, the impact of age of onset, the impact of progressive dual sensory loss, and the differences in language use and language acquisition. Uses Nordic definition of deafblindness: " a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to such a degree that society is required to facilitate specific services, environmental alterations and/or technology" The two focus groups included: (a) Five people (3 men and 2 women), all working age, all using spoken language. (b) Thirteen parents of children and adolescents with deafblindness.	Focus groups not organised for sign language users, those using tactile communication and older people reducing data available for these groups. When direct quotations from participants are used, information relating to age, age of onset and communication method of the participant is not always made explicit. Study involved multiple interpretation and translation activity.
Pavey et al. (2009) *The needs of older people with acquired hearing and sight loss.*	Research Knowledge	A research study, funded by the UK visual impairment charity Thomas Pocklington Trust, which explores the needs of older people with acquired dual sensory impairment.	Older people who have acquired hearing and sight loss in later life. Secondary data sources: relate	Participants recruited via specialist organisations of and for deafblind people: potential for bias. Study funded by charitable organisation

		The research had two phases. First, analysis of two pre-existing datasets (Network 1000 dataset and the Cambridge Dataset) relating to 609 older deafblind people and second, analysis of 20 case studies of older deafblind people. At the end of these phases, the researchers (from the University of Birmingham and the University of Cambridge) met with group of professionals in the deafblind field to discuss and validate the findings. Qualitative methods were used to analyse the data from both sources, supported by use of the computer software programme *NVivo*. Experiences of vulnerability were evident in the datasets. The research is published by the Thomas Pocklington Trust.	to people over 50 with later life acquired dual sensory loss. 20 Case Studies: Older people with later life acquired dual sensory loss. Age range: 58-92 years old; the majority (n=14) in 80s. 11 women and 9 men. 18 White British, 2 Indian. All but 1 had additional health problems or impairments.	for visually impaired people. Network 1000 dataset only included those registered with sight loss. Deafblind people may choose not to register or have a sight impairment that is not eligible for registration.
LeJeune (2010) *Aging with a Dual Sensory Loss: Thoughts from Focus Groups*	Research Knowledge	A USA based pilot study to inform the development of survey instruments for a larger research project: the Persons Aging with Hearing and Vision Loss (PAHVL Project). The PAHVL project is yet to report (mid 2014). Data were gathered from nine focus groups of 68 participants, exploring issues related to persons ageing with both hearing and vision impairment. Feelings of fear and vulnerability were discussed during the focus groups. Research is published in an online journal published by the Association for Education and Rehabilitation of the Blind and Visually Impaired.	Older People ageing with hearing and vision loss. Focus on those with single sensory impairment, acquiring a second sensory impairment in later life. Nine Focus Groups, total of 68 participants. 7 Focus groups concerned those who were visually impaired first and subsequently acquire a hearing impairment. 2 Focus groups concerned	Participants recruited via specialist organisations of and for deafblind people: potential for bias. In-depth analysis not undertaken. Demographic information not collected from all participants. No information on length of time between onset of first and second impairment.

			people who were deaf/hearing impaired first and subsequently acquired a sight loss. All but 1 participant aged over 55 (1 was soon to be 55). The majority of participants over 62. All individuals self-identified as having dual sensory impairment. All participants were members of consumer or support groups. Further demographic information collected from 39 participants: 20% African American; 80% White American 64% women; 36% men 31% blind, 69% visually impaired; 26% Deaf American Sign Language Users; 74% Hearing impaired speech users. 3 participants had a cochlear implant. 2 participants were in paid employment.	

Bodsworth et al. (2011) *Deafblindness and mental health. Psychological distress and unmet need among adults with dual sensory impairment.*	Research Knowledge	A UK based research study using the General Health Questionnaire (GHQ-12) to explore psychological distress amongst deafblind adults. The research also had a secondary aim of exploring unmet need amongst deafblind adults, by comparing reported levels of support with desired support. The Deafblind charity *Deafblind UK* supported recruitment by sending a self-report survey to all 2717 of their members; survey format was adapted depending on the communication needs of the members. 539 analysable surveys were returned. Data were analysed using SPSS (version 13.0). The research is published in the interdisciplinary, peer-reviewed *British Journal of Visual Impairment.*	539 participants. All members of the UK Charitable organisation Deafblind UK. All aged 18 or over. Age range: 18-104 years old. The mean age of the participants was 72 years old. 404 participants were over 50 years of age, and acquired deafblindness in later life. 36.2% were male, 61.3% female.	No age of onset information Participants recruited via a specialist organisation of and for deafblind people: potential for bias. Relatively low response rate Social work support identified as practical help rather than specialist support. In relation to care and support services, the extent of support offered to participants was not asked about.
Gullacksen et al. (2011) *Life Adjustment and Combined Visual and Hearing Disability /Deafblindness – an Internal Process over Time*	Research Knowledge	A Swedish follow up study to Göransson (2008). The aim of this research was to use a life adjustment model to analyse the experiences of living with combined visual and hearing disability / deafblindness. Data were gathered via focus groups. A topic emphasized in the focus groups was vulnerability. The results and analysis of the research are published in an online text by the Nordic Centre for Welfare and Social Issues.	Focus on acquired deafblindness and the authors use the term deafblind as a generic word for "acquired combined visual and hearing disability, according to the Nordic definition of deafblindness" 15 participants in total; three focus groups: Swedish, Danish and Norwegian. 4 men and 11 women. Aged between 25-65; majority aged between 35-50.	Participants recruited via specialist organisations of and for deafblind people: potential for bias. Age of participants given when direct quotations used, but not always age of onset. Interpreters used in data collection, but no acknowledgement that they are not neutral – lacks exploration and acknowledgement. Difficult to cross-reference data on age, age of onset and communication preferences.

			11 were congenitally Deaf/Hearing impaired and subsequently acquired sight loss. 4 were visually impaired from birth or childhood, and subsequently acquired hearing impairment. All had progressive impairment; majority (n=11) had Usher Syndrome. 9 participants used spoken language (supported by hearing aids and assistive technology). 6 participants used sign language: 4 visual sign and 3 tactile sign. 1 participant had a cochlear implant. Swedish Focus Group: all women communicating with sign language. Danish Focus Group: 3 women, 1 man, all communicating via spoken Danish. Norwegian Focus Group: equal number of men and women, using mix of communication methods.	

Kyle & Barnett (2012) *Deafblind Worlds*	Research Knowledge	A UK based research project, completed wholly in British Sign Language (and its deafblind variants). The aim of this study was to examine the experience of being Deafblind, to determine if this was similar to Deaf people's experience and to establish if Deaf and Deafblind people could work together. Qualitative data were gathered via interviews and group meetings. Interviewers were deafblind themselves. The themes of insecurity and vulnerability emerge from the data. Quantitative data were also gathered on the characteristics of the participants. The research has not yet been formally published, but the full report was retrieved directly from the first author.	21 participants. All used British Sign Language (and/or deafblind variants e.g. hands on or tactile sign language). Included congenitally deafblind people and people born Deaf, using British Sign language and identifying as a member of the Deaf community, subsequently acquiring a visual impairment. 85% of participants had hearing loss before the age of 5 years old. 41% acquired sight loss by the age of 10 years old. 6 men and 15 women. Age Range: 21-66 years old. 41% aged 21-35 years old. Six of the participants were aged between 51-65 years old. 77% used visual BSL by preference.	Age and age of onset of deafblindness not always made clear against participant direct quotations. Direct quotations presented in written English, but whole study completed in different modality (BSL).
Viljanen et al. (2012) *Fear of falling and coexisting sensory difficulties as*	Research Knowledge	A Finnish research study examining the combined effect of fear of falling and coexisting sensory difficulties on mobility. 434 participants were recruited from the Finnish	All participants were women and were aged between 63-76 years of age. 28% (n=122) of participants had two sensory impairments (a combination of	Age of onset not made completely explicit. Hearing impairment and visual impairment presented as separate

predictors of mobility decline in older women.		Twin Study on Ageing (FITSA) cohort. Data were gathered from a structured questionnaire and logistic regression was used to analyse the data. The research is published in the peer-reviewed *Journals of Gerontology: Medical Sciences.*	hearing impairment and/or vision impairment and/or balance difficulties); 10% (n=42) had three (hearing impairment, vision impairment and balance difficulties).	entities. Reference made to two sensory impairments not always indicative of deafblindness; in this study, this may refer to hearing loss and balance difficulties, or sight loss and balance difficulties. All participants were women and twins.
Hersh (2013) *Deafblind People, Communication, Independence, and Isolation.*	Research Knowledge	A research study exploring the experiences of deafblind people in six different countries (France, Poland, England, Italy, Spain and Czech Republic). The aim of this study was to explore issues related to communication, independence and isolation for deafblind people; it forms part of a larger research project, which explores travel issues for blind, visually impaired and deafblind people. Qualitative data were gathered from semi-structured interviews, based on a list of topics/themes, which were modified as the study progressed. Participants were interviewed by the author, who is from the Department of Biomedical Engineering, University of Glasgow. The data were analysed using qualitative methods; however, computer software was not used for analysis owing to the multi-lingual nature of the data. The themes of vulnerability and overprotection emerged from the data. The research is published in the peer-reviewed *Journal of Deaf Studies and Deaf Education.*	The term deafblind is used by the author to mean 'people with some degree of combined hearing and visual impairment'. She acknowledges that the 'deafblind people interviewed were very varied'. 28 participants from six different countries: 27 deafblind people and the mother of a deafblind woman with autism. Participants' ages ranged from below 16 years of age (n=1), to over 70 years (n=4). Age of onset of hearing impairment/ deafness and visual impairment is noted separately; ranges from birth to later life (60+).	Difficult to cross reference data on age, age of onset, communication method and severity of impairment. Limitations associated with interpretation and translation: • Whilst data analysis was undertaken in the language of the participants, direct quotations are presented in written English. • Non-verbal behaviours of those using tactile communication were not noted; this may impact on interpretation of participant responses, as such behaviours are important elements of meaning in tactual communication methods (Hart 2006). • Family members were used to interpret.

			14 women and 14 men. 68% participants used speech; 7% used speech and writing; 11% used visual sign language; 7% used tactile sign language; 7% used tactile alphabet and sign. 75% participants noted as blind, 17% as partially sighted; 36% participants noted as Deaf, 64% as Hard of Hearing. 7 participants had additional impairments.	Participants recruited via specialist organisations of and for deafblind people: potential for bias.
Stiefel (1991) *The Madness of Usher's. Coping with Vision and Hearing Loss (Usher Syndrome Type II.*	User Testimony	A personal account of living with Usher Type II written by a 60-year-old American woman, self-defined as 'now in her fifth decade of deafblindness'. The account is presented in book published by The Business of Living Publications, Texas.	A 60-year-old American woman (at time of publication), self-defined as ' now in her fifth decade of deafblindness'. Author has Usher Type II; born with hearing impairment and has experienced considerable depreciation of sight in last 25 years. She is a speech user.	Detailed account but based on personal experience. Author has particular background, not representative of all deafblind people – includes having had private education. Has contact with organisations of and for deafblind people.
Henderson (2000) *Coping with Usher Syndrome.*	User Testimony	A personal account of coping with Usher Syndrome, written by a 17-year-old girl with Usher Type I living in the UK. In the account, the author discusses her feelings about her diagnosis, the difficulties she encounters and her thoughts about	17-year-old young women diagnosed at 15 with Usher Type I. She experienced difficulties	Based solely on personal experience. Limited detail and depth.

		the future. The account is published in *The Lancet.*	with hearing from birth and used hearing aids up to the age of 13. Then refused hearing aids and used British Sign Language to communicate.	
Pollington (2008) *Always change – the transitions experience by an older woman with declining sight and hearing.*	User Testimony	A personal account of living and ageing with deafblindness, published in charitable organisation's (Sense) periodical. The author is a 68-year-old English woman who has been deafblind since her teenage years as a result of Usher Type II.	A 68-year-old English woman who has been deafblind since her teenage years as a result of Usher Type II. Born with hearing impairment and began to experience sight changes in childhood. Significant deterioration in sight in mid-40s. Communicates using speech and now uses braille to access printed material.	Based solely on personal experience.
Steve (Surname anonymous) (2012) *Is this social care enough?*	User Testimony	An opinion piece and personal reflection authored by a man deafblind and physically impaired as a result of Alström Syndrome. There are limited biographical details about the writer. The piece is published online by the UK charity Sense.	An adult man, deafblind and physically impaired (wheelchair user) as a result of Alström Syndrome. Experienced progressive visual impairment from birth (nystagmus and photophobia). Hearing impairment acquired subsequently (no details when). Hearing aid user and communicates using speech.	Very limited biographical information about the author. Focus on single issue: use of social care services. Presented as an online blog, so difficult to verify authorship.

Mar (1993) *Psychosocial Services: Presentation*	Practitioner Knowledge	A paper presented at the 1993 *National Symposium on Children and Youth who are Deaf-blind* in Monmouth, Oregon, USA. The paper was presented by H.H. Mar, a developmental psychologist who has worked as a counselor for deafblind people. The paper reviews current practices in the delivery of psychosocial services for deafblind people and explores how effective they are, particularly in meeting needs related to social and emotional well-being. The author draws predominantly on his own practice experiences, with some reference to other literature	Paper has a stated focus on 'children, adolescents and young adults who are deafblind'. The author 'sets the scene' to the paper by referring to a man in his 30s, congenitally deafblind as a result of Congenital Rubella Syndrome, and 'mildly mentally retarded' (sic). He goes on to acknowledge that his personal experience, on which the paper is largely based, is biased towards deafblind young people with cognitive disabilities.	Professional background of the author not made clear in the paper (this information was sourced elsewhere). The author acknowledges a bias toward deafblind young people with cognitive disabilities, but suggests the paper will also cover the psychosocial concerns of all deafblind individuals. It is not clear throughout the paper where this occurs as the author largely uses the single term 'deafblind' in much of the discussion.
Sauerburger (1993) *Independence without sight or sound. Suggestions for Practitioners Working with Deaf-Blind Adults.*	Practitioner Knowledge	A textbook published by the American Foundation for the Blind, New York and authored by an Orientation and Mobility (O&M) specialist/instructor who has worked with deafblind people at state rehabilitation agencies, private agencies and schools for over twenty years. The author predominantly draws on her own experiences, supported by reference to other published material, to offer practical suggestions, strategies and techniques for those working with deafblind adults.	The author uses a functional definition of deafblind: 'a person is deafblind is he or she has a combination of vision and hearing losses that together create a unique set of circumstances requiring adaptive techniques to function' (p1). The text draws on the author's experience of working with a range of deafblind people, including: Those profoundly deafblind;	Focus of the text is on practice and strategies for best practice, rather than the experiences of deafblind people. Whilst heterogeneity amongst deafblind people is acknowledged, details of the characteristics of deafblind clients discussed in the text are not always made explicit.

			those with residual hearing and/or vision; those with additional health problems or impairments (including learning disability); those with Usher Type I and II; those with congenital deafblindness, including those with congenital rubella syndrome; those born with visual impairment who subsequently acquire hearing loss; and those acquiring dual sensory loss in later life. The text focuses on deafblind adults not children.	
Smith (1993) *Psychosocial Services: Reaction*	Practitioner Knowledge	A paper presented at the 1993 *National Symposium on Children and Youth who are Deaf-blind* in Monmouth, Oregon, USA. The paper was presented by T. Smith, former director of the American Sign Language and Interpreting School of Seattle (1989-2007) and author of *Practical Tips for Working and Socializing with Deafblind People*. The paper is a reaction paper to that presented by H.H. Mar (1993). Smith draws on her experiences of working with deafblind people. She argues for the development of deafblind communities for this population.	The author draws on her experiences of working with deafblind people. She acknowledges that the majority of this experience is work with adults who are "just" deafblind: those with no additional intellectual impairment/learning disability; most of those she has worked with have Usher Syndrome. The paper discusses both deafblind children and deafblind adults.	The author is Director of the ASL and Interpreting School of Seattle. However, no information is provided on her professional background – this is problematic for a paper drawing on experiences. The paper contains no references to other literature, but it is not made clear if the author intends to draw solely from her knowledge from practice experience. She is the author of textbooks concerned with professional practice with deafblind people and has a PhD in the field. It is not clear if she is also drawing on this material.

Luey (1994) *Sensory Loss: A neglected issue in social work.*	Practitioner Knowledge	A practitioner paper describing the 'Hearing-Vision Project', in which the author co-ordinated the work of specialists in two agencies (one for hearing impaired people and one for visually impaired people), provided direct support and identified ways in which social workers might support the acquired deafblind population. The paper draws on the experiences of the author during the project, and an earlier exploratory study in which she interviewed 30 deafblind people. The author is a social worker at the Hearing Society for the Bay Area, Inc. San Francisco, California, USA. The paper is published in the peer-reviewed *Journal of Gerontological Social Work.*	Older people with late life acquired deafblindness. All clients of the 'project' were over 60 years of age (except 4 people with rare disorders). The median age is 87 years old. Just over 50% clients were women. 45% had a moderate hearing impairment; 10% severe hearing impairment 19% had total sight loss. More than 50% clients had an additional physical illness or impairment (e.g. arthritis, heart problems, diabetes).	The paper offers more description than analysis, and the focus is on service organisation rather than deafblind people's experiences. Limited information is given on the exploratory study. No information is given on the 30 deafblind people interviewed for that study.
Merkin & Smith (1995) *A community based model providing services for Deaf and Deaf-blind victims of sexual assault and domestic violence.*	Practitioner Knowledge	A report by the Education coordinator (Merkin) and Executive Director (Smith) of the Abused Deaf Women's Advocacy Services (ADWAS) in Seattle, Washington, USA. The paper describes the experiences of the authors in establishing a Deaf run agency providing services to Deaf and deafblind women experiencing sexual assault and domestic violence. At the time of publication, the agency was the only domestic violence service specifically for Deaf and deafblind women in the USA and had supported 28 deafblind adults.	Focuses on deafblind 'victims' of sexual assault and Domestic Violence. 28 deafblind people supported by the agency described in the article, with an age range between 4-76 (though this refers to both Deaf and deafblind users). Includes deafblind people using 'various communication	No further details on the 28-deafblind people supported (e.g. congenital or acquired deafblindness, age, age of onset, interval between sensory losses) are provided. Authors refer to 'various communication techniques', but no further detail is given. It is not always clear in the paper if the points being raised relate to Deaf and deafblind people, just Deaf people or

		The paper is published in the international, interdisciplinary and peer-reviewed journal *Sexuality and Disability.*	techniques'.	just deafblind people.
Miner (1997) *People with Usher Syndrome Type 2: Issues and Adaptations*	Practitioner Knowledge	A practitioner paper drawing on practice experience, other literature and interviews with adults with Usher Syndrome Type II over a four-year period. The author is a clinical social worker based in New York, USA at the time of publication, but now based in Los Angeles. The paper is published in the international peer-reviewed journal, *Journal of Visual Impairment & Blindness.*	Adults with Usher Syndrome Type II. The author interviewed 32 people over a four-year period. Author acknowledges that 'people with Type II are not an homogeneous group', with differences in language use and cultural affiliation. The age of some (not all) of the participants is given, and ranges between 24 and 45 years of age.	The demographic details of all the participants, including age, are not given. Nine of the 32 participants were clients or acquaintances of the author. The potential impact of this pre-existing relationship is not acknowledged or explored.
Moss & Blaha (2001) *Introduction to Sexuality Education for Individuals who are Deafblind and Significantly Developmentally Delayed.*	Practitioner Knowledge	A textbook published by the National Information Clearinghouse on Children Who Are Deaf-Blind and authored by a Family Support Specialist (Moss) and Teacher Trainer (Blaha) both from Texas Deafblind Outreach, Austin, Texas, USA. The book is aimed at parents, professionals, and others working with school-aged deafblind children with significant developmental delay. The book draws on literature related to sexuality education and deafblindness, conversations the authors had with parents and colleagues, and the	Focuses on deafblind children with additional significant developmental delay, defined as follows: 'a child with very rudimentary communication skills, is inwardly focused, and is not likely to seek out other people to engage in typical social interactions. The child often has additional physical disabilities and may be considered to be cognitively impaired'.	Lack of clarity in relation to the provenance of some of the knowledge referred to. This is a textbook, and focuses predominantly on service issues and best practice, rather than the detailed experiences of deafblind people.

		authors' own practices experiences whilst working at the Texas School for the Blind and Visually Impaired, and Texas Deafblind Outreach.		
Butler (2009) *Personal – Professional Relationships.*	Practitioner Knowledge	A practitioner authored piece describing the relationships between practitioners and deafblind people, and the potential for vulnerability within these relationships. The author draws on her own experiences, other research in the field and contact with other professionals and deafblind practitioners. The paper is published in the online version of *Talking Sense*, the magazine of the UK deafblind charity Sense.	The author largely focuses on acquired deafblindness, but includes deafblind children and adults. She draws some distinctions between deafblind people with learning disabilities, congenitally deafblind people and young deafblind people. The author illustrates some of her points with reference to a woman, now in her 50s, with progressive sight and hearing impairment since the age of 3.	Lack of detail in relation to the professional background of the author. Detail missing from the references. Largely draws on experiences with deafblind people known to the particular service.
Volden & Saltnes (2010) *Norway's new ways with mental health.*	Practitioner Knowledge	A short report by a Specialist Psychologist (Volden) and Senior Psychiatrist (Saltnes) from the National Centre for Hearing Impairment and Mental Health, which is part of Oslo University Hospital, Oslo, Norway. The report draws on the experiences of the work of the authors with a broad range of deafblind people; it also includes reference to other studies, though full citations for these are not offered. The report is published in the online version of *Talking Sense*, the publication of the UK deafblind charity Sense.	Focuses on deafblind people with mental health difficulties, including depression and psychosis. The report considers both congenitally deafblind people and those with acquired deafblindness, and acknowledges the range of differing communication needs amongst these populations. The paper specifically comments on issues for people	Full citations for references are missing. Lack of detail in general presentation. Greater focus on description of service and need for services, rather than the lived experiences of deafblind people.

			with a profound loss of hearing and vision, and people with Usher Syndrome.	
Wickham (2011) *Depression in the Deafblind Community: Working from a Social Work Perspective.*	Practitioner Knowledge	A practitioner paper drawing on practice experience and other literature to explore depression in the deafblind community, from a social work perspective. The author is a social worker for the Senses Foundation, Australia. The paper is published in the biannual publication of Deafblind International.	The author states that the paper is 'mainly related to adults with acquired deafblindness'. The paper considers those with progressive or sudden dual sensory loss and refers to a study of those living with deafblindness over a period of time.	Limited detail on the literature drawn upon. Insufficient information provided in order to locate study referred to. Refers to those with 'acquired deafblindness' but offers little further information in relation to age, age of onset and other characteristics.
Deafblind UK (2007) *Cause and Cure. Deafblind People's experience of the NHS.*	Organisational Knowledge	A report produced and published by the UK charity Deafblind UK, based on their health survey of deafblind people's experiences of the NHS in 2006 and the results of the first national survey of deafblind people and healthcare experiences in 2001 (Who Cares? Access to Health Care for Deafblind People) The 2006 survey was sent to all 2717 members of the organisation; 486 surveys were completed and returned. Some participants' surveys were completed with support.	486 surveys returned. All members of Deafblind UK. All deafblind adults. Reader can imply from the findings, that the participants use a range of communication methods, though this is not made explicit.	The method of analysis is not made explicit. No further information on participants (age of onset, age, congenital or acquired) is provided. Some of the surveys are completed with support or by proxies; difficult to determine impact of this. Produced by a campaigning charitable organisation for deafblind people.
Kiekopf (2007) *Reasons why deafblind individuals*	Organisational Knowledge	A paper presented at the 2007 Deafblind International World Conference in Perth, Australia. The lead presenter and named author is Steve	Main focus of the paper is congenitally deafblind people, children and adults. There is	Data relate specifically to deafblind people using the services of the organisation only.

are vulnerable to abuse.		Kiekopf, Policy and Quality Officer at the UK based deafblind charity Sense. The paper explores why deafblind individuals are vulnerable to abuse. The paper predominantly draws on data from the Sense Abuse Database over a five-year period (2000-2005) to contextualize the discussion. The Sense abuse database stores information on allegations and incidences of abuse amongst deafblind people using Sense services. In the period concerned, 94 incidences of abuse are recorded; this includes physical abuse, financial abuse, sexual abuse, psychological abuse and neglect. The paper also draws on some literature authored by practitioners in the fields of deafblindness and learning disability/intellectual impairment.	some separate comment on individuals with acquired deafblindness. Of the 94 incidences of abuse reported in the Sense Database between 2000-2005: 86 concerned congenitally deafblind people in residential or day service settings. 8 concerned older people with later life acquired deafblindness.	Produced by a campaigning charitable organisation for deafblind people. Some literature drawn upon relates to learning disability / intellectual impairment; this does not relate to all congenitally deafblind people. Details missing in the reference list.
Sense (2012) *Fair Care for the Future. Why social care matters for deafblind people.*	Organisational Knowledge	A report produced and published by the UK deafblind charity Sense, based on its survey of 89 deafblind people's experiences of social care in England and Wales.	89 deafblind adults, including those with congenital deafblindness and acquired deafblindness. Age Range: 18-80+ years Age of onset Range: Birth – 80+ years 67% (n=60) had other conditions in addition to deafblindness. Report includes 5 'case	The report includes limited information on recruitment processes and survey tools; direct quotations within the report are stated to be verbatim 46% (n=41) of returned surveys had been completed on behalf of the deafblind person. Cannot link the age and age of onset information. Relatively low response rate.

			studies': 1. 50-year-old woman, born profoundly Deaf, subsequent sight loss (registered blind), uses tactile BSL to communicate. 2. 22-year-old woman, congenitally deafblind, with additional impairments including epilepsy and learning disability. Uses own version of signed supported English to communicate. 3. 72-year-old man, dual sensory loss acquired in later adulthood, speech and hearing aid user. 4. 21-year-old woman, congenitally deafblind with additional physical impairment, learning disability (intellectual impairment); learning Makaton to communicate. 5. 24-year-old man with Wolfram Syndrome (DIDMOADS). Acquired	Produced by a campaigning charitable organisation for deafblind people.

			deafblindness, with progressive sight loss and profound bilateral deafness.	

2.7.2 Critical Interpretative Synthesis

2.7.2.1 Methodological and other limitations

Akin to the material reviewed in the first section of this chapter, no shared definition of deafblindness is evident across the 28 included references. For example, while Sauerburger (1993) and Danermark and Möller (2008) adopt a functional definition, with the latter using the reformulated Nordic definition (see Chapter One, section 1.2.1), Hersh (2013a:1) makes no reference to functional limitations in her definition, referring simply to 'some degree of combined hearing and visual impairment'. In the Viljanen et al. (2012) study, although some participants are deafblind, this is recorded as separate visual and hearing impairments, which are self-defined.

The literature relates to different sections of the deafblind population; as noted, these 'sub-populations' have very different experiences and needs (Moss and Blaha 2001, Department of Health 2009b) and therefore synthesis of the material must acknowledge this. Some material focuses solely or predominantly on congenitally deafblind people (Marks 1998, Kiekopf 2007) and some examines the experiences of those acquiring deafblindness, either in later life (Heine and Browning 2004, Pavey et al. 2009) or in early to middle adulthood (Danermark and Möller 2008, Gullacksen et al. 2011). While some material is related to deafblind people with additional intellectual impairment/developmental delay (Moss and Blaha 2001), Smith (1993) is explicit that she is considering those who are 'just' deafblind. The literature also refers to deafblind people of different nationalities; the review includes a Finnish study (Viljanen et al. 2012), and material from the USA (see, for example, Stiefel 1991, Miner 1997, LeJeune 2010), Australia (Heine and Browning 2004), Sweden (Göransson 2008, Gullacksen et al. 2011) and the UK (see, for example, Pavey et al. 2009, Bodsworth et al. 2011, Kyle and Barnett 2012). Hersh's (2013) study involved participants from six different countries. Perspectives on disability and impairment, and the organisation of health and social care services differ across these countries (Ingstad and Whyte 1995, Glendinning and Bell 2008), which may influence the experiences of the participants.

Methodological limitations similar to those noted in section 2.6.2.2. are also evident. For example, challenges posed by interpretation and translation in qualitative research are apparent, particularly in Hersh's (2013) study. Although Hersh (2013) reports that data analysis was undertaken in the language of the participants, direct quotations are presented in written English. Furthermore, Hersh (2013) acknowledges that non-verbal behaviours of those using tactile communication were not noted; this may impact on interpretation of the responses of these participants, as such behaviours are important elements of meaning in tactual communication methods (Hart 2006). Hersh (2013) also states that family members were used to interpret; this raises both methodological and ethical issues. Such family members are non-neutral constructors of knowledge (Temple 2002), who may, albeit unintentionally, omit or embellish information from the participant (Regmi et al. 2010). Furthermore, they do not necessarily have the skill level, professional status or registration (including commitment to a code of ethics) of qualified interpreters.

In the majority of included primary studies, participants were known to and recruited via specialist organisations of and for deafblind people (Heine and Browning 2004, Göransson 2008, Pavey et al. 2009, LeJeune 2010, Bodsworth et al. 2011, Gullacksen et al. 2011, Hersh 2013). Most authors acknowledge the potential for bias that this engenders (Padgett 2008). The two literature review papers (Marks 1998 and Danermark and Möller 2008) provide little to no information on how the literature used was found, selected and appraised. Furthermore, Marks (1998:200) relates the literature used to 'best practices in teaching children who are deaf-blind'; there is no indication in the paper detailing how these best practices have been identified or validated.

Relatively low response rates to surveys and completion by proxies (Deafblind UK 2007, Sense 2012), a lack of information on professional backgrounds (Butler 2009), missing full citations (Volden and Saltnes 2010) and lack of clarity in relation to the provenance of knowledge (Moss and Blaha 2001), all impact on the rigour of the practitioner and organisational knowledge. Consideration must also be given to the potential for bias owing to the fact that the producers of the organisational knowledge (and funder of one of the primary studies (Pavey et al. 2009)) are campaigning charitable bodies for sensory impaired people (Salkind 2014).

The personal accounts are limited in detail and depth, offering only a snapshot of the authors' life experiences. They are also not representative of the experiences of all deafblind people. In particular, the account from Steve (Surname not known) (2012) offers very limited biographical information and largely focuses on a single issue: the use of social care services.

Although the material included had limitations as described, common themes addressing the review question were identified: reasons why deafblind people are considered vulnerable; identification of deafblind people as a group 'at risk'; and deafblind people's own descriptions of their experiences of vulnerability and being vulnerable. These are considered next.

2.7.2.2 Why are deafblind people considered vulnerable? Is this all deafblind people?

The identification of deafblind people as a 'vulnerable group' is evident in sensory services best practice standards (Hutton 2000), material published by specialist organisations (see, for example, Sense 2014) and also across the literature reviewed. This includes older deafblind people (Göransson 2008, LeJeune 2010), deafblind adults (Danermark and Möller 2008) and deafblind children and young people (Moss and Blaha 2001). In their reflections on the work of the Secretariat of the African Decade of Persons with Disabilities, Sarr and Dube (2010:7) refer to deafblind people as one of 'the *most* vulnerable groups' (my emphasis); they do not comment further on this status nor offer their reasons for such classification. Moss and Blaha (2001) and Kiekopf (2007), writing in the context of abuse, focus more specifically on the reasons why deafblind people are considered vulnerable. Noting that such reasons are complex and interlinked, Kiekopf (2007) contends that deafblind people's vulnerability is amplified by the main difficulties associated with the impairment: communication, mobility and access to information.

The communication challenges posed by deafblindness, particularly, though not limited to, those congenitally deafblind (Kiekopf 2007, Hart 2008) may result in deafblind individuals being unable to disclose abuse, increasing their vulnerability (Moss and Blaha 2001, Kiekopf 2007). Congenitally deafblind individuals may lack the necessary language and vocabulary to describe or disclose abuse, particularly sexual abuse (Moss and Blaha 2001, Kiekopf 2007); consequently, potential abusers may view them as safe victims (Kiekopf 2007) and criminal justice professionals as unreliable witnesses (Moss and Blaha 2001). Kiekopf (2007) observes that data taken from the Sense Abuse Database for a five-year period (2000-2005) reveal that in just 9.5 per cent of cases (*n* = 94) was the abuse disclosed by the victim.

Arguing that an inability to explore one's environment, anticipate attack and move away quickly to defend oneself all increase vulnerability, Kiekopf (2007) is the only author to comment on the impact of mobility difficulties on the vulnerability of deafblind people. Limited access to information as a contributing factor is reported more widely. Low levels of information about sexuality and 'sexual rules' (Moss and Blaha 2001), the environment (Marks 1998), and the sequence of events, including those related to care and support (Kiekopf 2007, Göransson 2008, Kyle and Barnett 2012) may result in deafblind people being confused about what is acceptable and non-acceptable behaviour towards them (Kiekopf 2007). In some situations, deafblind individuals may tolerate abusive behaviours, perceiving them as normal or as sensory experiences (Moss and Blaha 2001, Kiekopf 2007).

A lack of information and dependence on others for information (particularly where communication is received tactually on a one-to-one basis) may also result in low levels of assertiveness and independent decision-making (Sauerburger 1993, Hersh 2013). Pollard et al. (2000:231-232) claim that, although a highly heterogeneous population, deafblind people:

> have historically shared the common experience of those who are not disabled controlling most of the decisions…. that have shaped their lives.

Marks (1998) argues that such passivity, particularly if developed in early life, results in a situation of learned helplessness among deafblind children. Such learned helplessness has been linked to deafblind children's lack of resistance to sexual abuse (Moss and Blaha 2001) and an increased risk of sexual assault and domestic violence for deafblind women (Merkin and Smith 1995).

Associated with deafblind people's communication, mobility and access to information difficulties is social isolation (Mar 1993, Smith 1993, Bodsworth et al. 2011). Smith (1993:24) maintains that deafblindness 'can be an incredibly isolating .... experience'. High levels of isolation have been associated with increased vulnerability among deafblind people (Mar 1993, Göransson 2008); this includes vulnerability to abuse (Moss and Blaha 2001, Bodsworth et al. 2011), vulnerability to psychological distress (Bodsworth et al. 2011) and heightened emotional states (Butler 2009).

In addition to matters related to communication, mobility and access to information difficulties, Kiekopf (2007) posits that the interactions and relationships between deafblind people and health and social care practitioners may impact on levels of vulnerability. Numerous professionals may be involved in providing care and support (Kiekopf 2007, Danermark and Möller 2008) and, while many deafblind people achieve a significant level of independence (Alley and Keeler 2009, Kyle and Barnett 2012), high levels of dependence on others are noted in the research and practitioner knowledge (Sauerburger 1993, Moss and Blaha 2001, Kiekopf 2007, Danermark and Möller 2008, Bodsworth et al. 2011, Gullacksen et al. 2011). This can include what Marks (1998:208) identifies as 'extreme dependence', owing to one-to-one support needs, and also relates to both congenitally deafblind people and those with acquired deafblindness. Such high levels of dependence on others have been linked to increased vulnerability to abuse (Calderbank 2000, Association of Directors of Social Services 2005, Hague et al. 2011). Kiekopf (2007), Danermark and Möller (2008) and Butler (2009) all observe that deafblind people may learn that those providing support are safe, and Sauerburger (1993) describes working with deafblind people who are very surprised to learn that the public are unclear about deafblindness and deafblind people's needs. Such perceptions, combined with public and professional misperceptions that disabled children, including deafblind children, are not abused (Moss and Blaha 2001, Stalker and McArthur 2012), may also increase their vulnerability to abuse.

A feature of any interaction with deafblind people is touch. The topic of touch, in the context of professional relationships, has been explored by both practitioners and deafblind people (Sale 2007, Butler 2009, Mann 2009, Krijger 2011). The material reviewed suggests it is also associated with vulnerability. Touch is often essential when making contact and communicating with deafblind people (Kiekopf 2007, Göransson 2008). For deafblind children with additional developmental delay, Moss and Blaha (2001:11) identify touch as 'one of the primary teaching and learning tools'. They add that deafblind children receive more touch than their peers and as a result are more comfortable with it. Kiekopf (2007) argues that deafblind people learn that it is acceptable to be touched. This could be by several people, including family members, peers, and health and social care practitioners (Moss and Blaha 2001, Kiekopf 2007); it also includes people not close to nor chosen by the deafblind person (Göransson 2008). Some of this touch may be of a more intimate nature than would be considered appropriate touch between non-intimate partners according to normative standards (Sauerburger 1993, Moss and Blaha 2001). As such, Smith (1993) suggests that deafblind people receive mixed messages about appropriate touch. She also notes, as does Göransson (2008), that deafblind people may lack information on and awareness of the social and cultural rules of touch and personal space. In the context of vulnerability to sexual abuse, Moss and Blaha (2001) highlight that this includes lack of awareness about private areas of the body. While these factors may heighten deafblind people's vulnerability, it is also evident that use of touch may increase practitioners' sense of vulnerability. Sauerburger (1993) describes situations where deafblind service users have expressed the desire for an embrace when she has arrived or when departing. Moss and Blaha (2001:52) contend that deafblind adolescents may 'respond sexually to touch', albeit non-sexual touch. Close physical contact is both necessary in interaction, but also a potential source of vulnerability for both the deafblind person and the practitioner. Reflecting on the relationship between deafblind people and social workers, Krijger (2001:12), a deafblind woman, suggests that this physical contact 'easily leads to a closer bond' and that therefore 'the relationship between the deafblind client and social worker carries a very complex interaction'. Vulnerability is therefore mutual.

Identification of the reasons for deafblind people's vulnerability is apparent across much of the literature reviewed. Nonetheless, it is important to acknowledge that the material with a particular focus on this topic, namely, Moss and Blaha (2001) and Kiekopf (2007), is predominantly concerned with certain sub-sections of the deafblind population: deafblind children with significant developmental delay and congenitally deafblind people. Although Moss and Blaha (2001:95) maintain that it is the needs associated with additional deafblindness that make those with intellectual impairments 'a very vulnerable group', generalisations cannot be made across the deafblind population. The causes of heightened vulnerability identified do not always, therefore, relate to all deafblind people. Ironically, Smith (1993:28) argues that the tendency for all deafblind children to be 'lumped together as a category' may itself increase the vulnerability of those children who are 'just' deafblind, as their needs can be overlooked.

2.7.2.3 Vulnerable or 'at risk'?

Deafblind people are identified as being 'at risk' of various dangers or harms when compared to the non-deafblind population. Moss and Blaha (2001) and Kiekopf (2007) both consider the risk of abuse. While Moss and Blaha (2001:107) focus on sexual abuse, noting a 'very great risk' for deafblind children with developmental delay compared to 'their typical peers' (*ibid.:*96), Kiekopf (2007:23) suggests that deafblind people are 'potentially [at] greater risk' of all forms of abuse. Merkin and Smith (1995) identify deafblind women as being at risk of long-term sexual assault and domestic violence, partly as a result of early life passivity and learned helplessness. Passivity and lack of information in relation to decision-making are also linked to 'unusual' financial decisions, which may place deafblind people at greater risk of exploitation and financial abuse (Pavey et al. 2009).

Practitioners identify deafblind people as being at risk of specific dangers associated with daily living (Sauerburger 1993, Luey 1994). This includes accidents within the home, while travelling and when crossing roads. Luey (1994) describes such risk as stressful and linked to feelings of vulnerability. Nevertheless, such specific dangers are mentioned infrequently by deafblind participants in the research literature (see section 2.7.2.4). In contrast to the notion of being at greater risk than the non-deafblind majority, Murphy (1991:170), in his brief account of living with deafblindness, states:

> I also occasionally cut a finger on a knife or burn myself by touching a hot pan, or scald myself with steam; but who does not have such little accidents…. I have yet to hear of a sighted-hearing person who has never had such little accidents.

Within the practitioner and research knowledge, and associated with communication and independent travel difficulties, is identification of the high risk of social isolation (Mar 1993, Sauerburger 1993, Smith 1993, Moss and Blaha 2001, Volden and Saltnes 2010, Bodsworth et al. 2011, Hersh 2013). Social isolation is not only identified as something to which deafblind people are at risk, but also as a contributor to heightened risk of abuse and mental health difficulties (Moss and Blaha 2001, Volden and Saltnes 2010, Bodsworth et al. 2011). High levels of social isolation were not described by the participants in Kyle and Barnett's (2012) study. However, it is acknowledged by the authors that these participants were 'more confident', 'already in contact with organisations' and 'those who have friends who were also deafblind' (*ibid.:*42).

As described in section 2.6.2.3, deafblind people experience ongoing change and necessary adaptation throughout their lives, owing to the interaction between a fluctuating impairment and the environment. Therefore, it is unsurprising that deafblind people are identified as being at greater risk of ontological insecurity (Danermark and Möller 2008). Marks (1998), Deafblind UK (2007), Danermark and Möller (2008), Göransson (2008) and Kyle and Barnett (2012) all refer to the connection between constantly changing routines, uncertain events, unfamiliar environments, lack of control and information, and increased risk of stress and insecurity. Göransson (2008:52) observes that deafblind people face uncertainty 'perhaps on a daily basis' and unfamiliar environments and an inability to predict events are considered particularly problematic. Kyle and Barnett (2012:82) report that:

> [i]nsecurity arose in unknown environments or where the layout had been changed. In situations of change, insecurity becomes a real problem and we begin to *enter the domain of vulnerability* (my emphasis).

Miner (1997) suggests that ontological insecurity among deafblind people may be linked to increased risk of mental health problems. While studies recognise deafblind people as being at risk of further physical health problems, in part owing to late manifestations of their conditions (Laustrup 2004, Gullacksen et al. 2008), the identification of deafblind people as a group at greater risk than non-deafblind people of emotional and mental health difficulties is also apparent across the literature reviewed. As noted in section 2.3.1, it is difficult to determine whether deafblind people are at greater risk of mental health problems than the general population. Nonetheless, Bodsworth et al. (2011) found higher levels of psychological distress amongst the deafblind people they surveyed (*n*=539) than among the general population. Drawing on his experience as a developmental psychologist, Mar (1993:12) argues that deafblind people are 'more vulnerable than most other persons to … emotional instability' and that the 'incidence of major psychiatric and psychological problems…among [deafblind people] is extremely high' (*ibid.:*11). Focusing specifically on depression, Wickham (2011:58) argues that the risk of deafblind people developing this condition 'has been clearly identified', although Volden and Saltnes (2010) note that depressive illness among deafblind people may result from a number of complex, inter-related factors.

Case studies reporting on the diagnosis, assessment and treatment of psychosis in people with Usher syndrome appear in clinical literature (see, for example, Waldeck et al. 2001, Rijavec and Grubic 2009 and, Viala et al. 2009). These explore a potential link between Usher syndrome and psychotic illness. Volden and Saltnes (2010) refer to studies suggesting that those with Usher syndrome are more at risk of psychosis. Nevertheless, Danermark and Möller (2008:121) assert that 'psychiatric condition is not found to be an integral part of Usher'.

Mar (1993), Bodsworth et al. (2011) and Wickham (2011) all maintain that the risk of mental health difficulties faced by deafblind people is exacerbated by a lack of specialist and appropriate services. Furthermore, owing to communication difficulties (Mar 1993, Deafblind UK 2007, Hersh 2013) and misinterpretation of the effects of sensory impairment (Sauerburger 1993, Miner 1997, Wickham 2011), deafblind people are identified as a group at risk of misdiagnosis of mental health conditions.

Kyle and Barnett (2012:59) observe that the risk of insecurity, social isolation and associated vulnerability are considered by care and support services as 'justification for intervention'. However, Sauerburger (1993) and Kyle and Barnett (2012) identify that for many deafblind people, it is more important to feel in control of one's life, rather than be protected by the intervention of others. There is therefore a risk of over-protection, when the perspectives of deafblind people themselves are not considered

(Kyle and Barnett 2012, Hersh 2013). Some of these perspectives are evident in the literature.

2.7.2.4 What do deafblind people themselves say they feel vulnerable about?

Deafblind people's descriptions of feeling vulnerable are apparent across the material reviewed. In Luey's (1994) exploratory study, deafblind people discuss their experiences of vulnerability, and interview data in Kyle and Barnett's (2012) research reveal expressions of feeling vulnerable. Participants in Gullacksen et al's (2011) study offer various examples of times they have felt vulnerable; Gullacksen et al. (2011:30) report that vulnerability is one of the 'topics *emphasized* by the focus groups' (my emphasis). Interpreting data from focus groups with older deafblind people, LeJeune (2010:7) refers to the:

> deep personal anxiety and fear some people described experiencing as they faced the last decades of their lives with reduced vision and hearing.

Some deafblind people express an overall feeling of vulnerability, which is often associated with being alone. One participant in LeJeune's (2010:7) focus groups describes feeling 'very alone and often frightened' and Henderson (2000:S18), a 17 year-old girl with Usher syndrome, describes feeling 'scared and alone' following diagnosis. For some deafblind people, it is going out alone which results in feelings of vulnerability, while others describe feeling vulnerable both outdoors and in their own homes (Sense 2012). An older participant in Göransson's (2008:145) study states:

> It is not very safe to live *on your own* when you can neither see nor hear (my emphasis).

Sauerburger (1993) notes that some deafblind people are worried that they will always be alone. Furthermore, with reference to the experiences of one of her service-users, she highlights that not being alone is associated with no longer being vulnerable or afraid (*ibid.*). While deafblind people may acknowledge their own inherent risk factors, it is the challenge to self of being alone and the perception that being alone renders one unable to respond to the potential for harm that lead to feelings of vulnerability.

Some deafblind people, particularly those who are older, describe feeling vulnerable to specific physical harms or dangers. This includes fear of falling (Pavey et al. 2009, Viljanen et al. 2012), fear of being a victim of crime (Pavey et al. 2009, Kyle and Barnett 2012) and of accidents in the home (Sense 2012). Lack of control over the environment appears central to these fears. For example, in the context being a victim of crime, a participant in Kyle and Barnett's (2012) study relates such fear to being unaware, when alone, about who is coming into the home; a respondent to the Sense (2012) social care survey relates her fear of falling, to a lack of control in the home environment when alone. Kyle and Barnett (2012:47) also observe that fear of specific dangers or harms is intrinsically linked to being unable to access the environment by touch, thus resulting in a lack of control:

> fear arises from not being able to touch or make contact with anything around. Without physical contact, confidence in the wider environment drops to zero… Fear of this situation of *lack of control* commonly leaves the Deafblind person feeling vulnerable (my emphasis).

Lack of control appears to be more significant in deafblind people's descriptions of vulnerability, than identifying specific dangers. Participants in the research by Göransson (2008), LeJeune (2010), Gullacksen et al. (2011), and Kyle and Barnett (2012) all describe feeling insecure, frightened and vulnerable as a result of perceiving themselves to be losing control over the environment or events happening around them. Participants in Göransson's (2008) study describe feeling insecure in relation to events not 'turning out' as they had planned; specific examples are given of such situations, including a bus not taking a usual route or an interpreter failing to arrive as planned. Lack of control and consequent feelings of vulnerability are particularly evident for deafblind people when they are in unfamiliar environments (Stiefel 1991, Deafblind UK 2007, Göransson 2008, LeJeune 2010 and Kyle and Barnett 2012). However, it is not just lacking control of the physical environment that results in vulnerability, but also loss of control in relation to events occurring and an ability to interpret these. Stiefel (1991:54) states that:

> [l]osing the ability to make valid, perceptive judgments about what I have seen and/or heard makes me feel very vulnerable…. How awesome and frightening to watch yourself losing control of the real world and not have the skills to know how to keep up with…others.

Although some deafblind people describe vulnerability as being associated with a lack of control and being alone, others report feeling vulnerable to overprotection

(Sauerburger 1993, LeJeune 2010, Hersh 2013). Such overprotection can take active forms (for example, restricting activities) or passive forms (for example, withholding certain information) (Hersh 2013) and deafblind people describe feeling overprotected by both family members (LeJeune 2010) and health and social care professionals (Sauerburger 1993, Hersh 2013).

Those with progressive conditions, such as Usher syndrome, report feeling vulnerable about the future. For some, their fears are related to further sensory loss (Miner 1997, Henderson 2000) and the ability to cope with further impairment (Gullacksen et al. 2011). LeJeune (2010:6) describes the fear of the effects of further sensory loss expressed by her focus group participants as 'overwhelming for many'. Older deafblind people in Pavey et al's (2009) study describe anxiety about future deterioration of health generally and the health and social care services that will be available to them. Nonetheless, deafblind people's relationship with health and social care services is not just a future concern but relates to present feelings of vulnerability. For participants in Kyle and Barnett's (2012) study, social care services, such as communicator-guides, are perceived as an important resource in responding to challenge:

> I might shout the name of my guide, the guide comes and I am relieved (*ibid.:*47)
>
> That's why I have a guide with me all the time, so I feel safe (*ibid.:*47)
>
> If my communicator-guide stays with me; they would explain that I was deaf and blind so I would not need to panic (*ibid.:*59).

Butler (2009) also refers to service users reporting feeling safe when with professional staff with whom they have a close relationship. Participants in Göransson's (2008) and Gullacksen et al's (2011) studies, and Pollington (2008) in her personal account, describe feeling frustrated and fearful about services being unavailable or inaccessible, both now and in the future:

> I have applied for transport services home when I work evenings during the winter. My application has been rejected four times. You *feel vulnerable* when things that could make you stronger are rejected (Participant in Gullacksen et al. 2011:62; my emphasis).

Those already in receipt of services express feeling vulnerable to these services being reduced or stopped (LeJeune 2010, Sense 2012, Steve (surname not identified) 2012).

There is also concern that services will be unable to meet needs. Göransson (2008) observes that some deafblind people feel particularly unsafe when accessing health care services; this is mostly associated with fears that communication difficulties will result in their needs being misunderstood. Respondents to Sense's (2012) survey of social care experiences report having concerns about their needs not being appropriately recognised in the assessment process. Data from health and social care surveys by Deafblind UK (2007) and Sense (2012, 2014) and research by Bodsworth et al. (2011) reveal numerous negative experiences of accessing and using such services in the UK, suggesting that deafblind people's feelings of vulnerability in this setting are not without foundation.

Smith (1993:23) argues that intellectual impairment and deafblindness 'have become inappropriately combined in the minds of… [health and social care] staff'. This may be a result of those being born deafblind and now in adulthood, not having their dual sensory impairment recognised and as such being considered to be developmentally impaired (Göransson 2008). Nevertheless, although deafblindness poses a number of challenges, as observed by a deafblind participant in Gullacksen et al's (2011:21) study, 'losing one's abilities is not the same as losing one's competence'. Deafblind people describe feeling vulnerable to being perceived as 'incompetent' (Miner 1997), 'chronically confused' or 'mentally deficient' (Stiefel 1991), 'pathetic' (Pollington 2008) or even 'mentally ill' (LeJeune 2010). This perception, by both the public (LeJeune 2010) and by professionals (Deafblind UK 2007), is considered to have a negative impact on life experiences, as explained by participants in Bodsworth et al's (2011) study:

> [I am] perceived as someone who is unable to speak for themselves, which is not the case. I am not learning disabled (*ibid.:*19).
>
> I have dual sensory loss. I am not mentally retarded and don't like being treated as such (*ibid.:*19).

As a consequence of both these misperceptions and communication difficulties, some deafblind people describe feeling vulnerable in social situations. Feelings of embarrassment, fear, anxiety and distress in social situations are described by deafblind people across the literature (Stiefel 1991, Sauerburger 1993, Göransson 2008, Gullacksen et al. 2011, Kyle and Barnett 2012). Participants in Heine and Browning's (2004:123) study are described as 'fearing' such situations and report that communication difficulties cause 'immense anxiety'.

2.8 Discussion

2.8.1 Ageing With Deafblindness

Charitable organisations for older people have campaigned 'for greater rights for older people without making reference to disability rights explicitly' (Phillips *et al.* 2010:77). Similarly, connections between disability and ageing theory are not always made (Oldman 2002); Putnam (2002) maintains that several theories of ageing fail to examine the impact of life-long disability in particular. Priestley and Rabiee (2002) observe a paucity of studies on disability in later life and there is a particular dearth of research exploring the experiences of those ageing with impairments. Writing as an adult ageing with disability, Newell (2008:74) argues that:

> [t]he ageing of adults with all types of disabilities is an important issue which has not necessarily received the intellectual energy that it should.

Reflecting this research gap, a rigorous and systematic search found no studies focusing solely and specifically on the experiences of those ageing with deafblindness: as noted in section 2.3.1, those ageing with the impairment are a hidden sub-group of the deafblind population. Nonetheless, studies of those ageing with impairments are emerging, and these identify certain themes: ongoing life changes, related to both impairment and ageing, and a consequent need for adaptation; the effects of ageing being experienced as a 'second disability'; and anxiety related to maintaining independence (Zarb and Oliver 1993, Gilson and Netting 1997, Jeppsson Grassman et al. 2012). Such experiences are reported in the literature relating to those ageing with deafblindness, and may be considered features of what Putnam (2012:92) describes as the 'uniqueness to ageing with disability'.

Those ageing with deafblindness describe the experience of ongoing change and consequent adaptation, an experience similarly reported by adults ageing with physical impairments (Zarb and Oliver 1993, Jeppsson Grassman et al. 2012). Adopting the concept of a 'career', Zarb and Oliver (1993) explain that those ageing with impairments often have to make repeated adaptations; such a concept could be used to describe the ongoing adaptations made by deafblind people as they age, particularly in relation to communication changes, which may necessitate the learning of new methods. The disability movement, disability activists and disability studies academics, particularly those adopting a 'strong' social model of disability, are nevertheless critical of the use of a model of individual adjustment to explain the experience of disability over the life course (Shakespeare and Watson 2001, Oliver et al. 2012). They argue that such an individual adjustment model neglects the wider social situation. Göransson (2008) and Gullacksen et al. (2011) acknowledge that adjustment is not just an individual response to impairment, and observe that as deafblind people get older they also need the social environment and service providers to adjust. For example, when a deafblind person learns a new communication method to respond to changing levels impairment, so too must others, in order for communication to be meaningful and indeed, to be established. This need for others to adjust is not always acknowledged in the deafblind literature (Hersh 2013).

The relationship between the effects of ageing and deafblindness, and the reciprocal, often exacerbating impact they have on each other is also observed in studies of those ageing with other impairments. This includes further physical limitations, reduced social networks, and increased isolation. Furthermore, the interpretation of the experience of ageing with deafblindness as 'accelerated' ageing is similarly found in the descriptions of those ageing with both physical impairments (Zarb and Oliver 1993, Jeppsson Grassman et al. 2012) and learning disabilities (intellectual impairment) (Foundation for People with Learning Disabilities 2002, Ward 2012). In their quantitative study of older people living in The Netherlands (n=624), although Kempen et al. (1998) found limited support for the hypothesis that the co-occurrence of age related impairments exacerbated the experience of disability in later life, sensory impairment was observed as exacerbating the disabling effect of other impairments as participants aged. Notwithstanding such findings, the impact of the relationship between ageing and impairment is not always experienced negatively. For example, participants in Jeppsson Grassman et al's (2012) studies report feeling less concerned about their bodies as they aged, mirroring the reflections in Pollington's (2008) personal account of ageing with deafblindness.

Some older deafblind people report that living with the impairment over time made future adjustments easier. Others explain that coping with deafblindness does not get easier, and for some, as they got older, things became harder. People ageing with physical impairments describe similar experiences, and ongoing difficulties are perceived as threatening their independence (Zarb and Oliver 1993, Jeppsson Grassman et al. 2012). However, not all those ageing with impairments express a desire to be independent (Zarb and Oliver 1993) and as found in this review, this includes those ageing with deafblindness: rejecting independence, Barr (1990) states a clear wish for assistance or a 'helping hand'. Nonetheless, this may reflect differing interpretations of independence. In redefining the concept, the disability movement argues that it does not relate to the refusal of or lack of need for assistance, but rather concerns being in control of how and when that assistance is provided (Morris 2004). Comparably, research exploring the meanings older people ascribe to independence highlights that many view remaining autonomous and in control, *inter alia*, to be as important as being able to care for one self (Secker et al. 2003). These interpretations of independence have influenced UK adult social care provision, most notably through the use of direct payments and personal budgets (Prideaux et al. 2009). Evidence that such services can promote positive outcomes (Netten et al. 2012, Woolham and Benton 2013) suggests that they should be made available to those ageing with impairments, including deafblind older people.

Minkler and Fadern (2002) argue that the 'successful ageing' paradigm (Rowe and Kahn 1998) is problematic from a disability perspective, owing to its emphasis on the avoidance of disease and disability, maintenance of physical function, and advocacy of individual behaviour modification. A life lived with impairment does not necessarily make it easier for people to avoid or face further impairment or ill health, nor is an existing life-long impairment experienced as static. For example, while congenitally deafblind people may not have a fully developed proprioceptive sense (Sauerburger 1997, Brown 2006), those ageing with the condition may experience further decline in proprioceptive function as they age, because of changes in the peripheral and central nervous system (Goble et al. 2009). This may be particularly challenging for those who have relied on the range of sensory systems encompassing 'touch', impacting on their balance and ability to complete other sensorimotor tasks (Brown 2006). In their systematic review of studies examining the meanings older people themselves attribute to successful ageing, Bowling and Dieppe (2005) observe that, in addition to maintaining health and function, enjoying life and being socially active were considered important. This review shows that, in later life, some people ageing with deafblindness are learning new skills, working, actively engaging with rehabilitative services, and making new friends. Case study examples of older people ageing with deafblindness learning new skills much later in life have also been presented at inter-disciplinary conferences (Jenson and Christiansen 2011, Schoone and Snelting 2011). These experiences represent a direct challenge to the social construction of old age as a period of inevitable decline and withdrawal (Andrew 2012) and support the assertion of Kelley-Moore (2010:106) that:

> … persons who are ageing with disabilities… tend to be more proactive in the planning and management of potential long-term care needs.

Those ageing with deafblindness appear to value care and support services. This review highlights their concerns about ongoing service availability, accessibility and funding for support. Such concerns are evident in the literature on both ageing with deafblindness and the vulnerability of deafblind people, and the theme is apparent in studies with those ageing with both physical and intellectual impairments (Jeppsson Grassman et al. 2012, Ward 2012). For Bejsnap (2004:72), an older person deafblind from adolescence, it is lack of support that is central to the experience of *being* deafblind, rather than the impairment itself:

> As soon as I let go of my interpreter, I am deaf and blind and all alone in the world. But when I am in contact again with my interpreter, I can communicate and get information about what's going on around me.

Ensuring appropriate care and support services requires the development of our knowledge and understanding of the unique experience of those ageing with impairment, recognising the differences between this population and those ageing into disability. Nevertheless, Verbrugge and Yang (2002) warn that distinction between these groups can be simplistic. They argue that disability and ageing interweave throughout the life course, and that it is essential to view them as intertwined (*ibid.*).

More detailed understandings are therefore required, necessitating further research and theorizing in the field of disability in later life.

2.8.2 Deafblindness and Vulnerability

A common approach to vulnerability involves the objective identification, description and categorisation of people with particular needs as a vulnerable or at risk group (Satz 2008, Fawcett 2009). Arguably, the vulnerability of deafblind people is considered axiomatic; statements appear in the literature identifying deafblind people not only as a vulnerable group but also as one of the most vulnerable. Reflecting an etic perspective on vulnerability, as described in Chapter One (see section 1.4.1), deafblind people are identified as a population at risk of a range of harms or adverse outcomes, particularly when compared to the non-deafblind majority. This includes being at risk of abuse, poor physical health outcomes, mental ill health, ontological insecurity and social isolation. Risk factors are located within the individual (for example, communication difficulties, learned helplessness or lack of independence), but the determination of the level of risk is made by comparison to normative standards. Such comparison is often made by health and social care professionals, who are thus involved in determining which individuals and groups are at higher risk, and therefore considered vulnerable (Spiers 2000).

Although such categorisation can offer 'useful preliminary sorting' (Schröder-Butterfill and Marianti 2006:15), identifying deafblind people as a vulnerable group is problematic. Resembling other groups attributed the label 'vulnerable' (Fawcett 2009), deafblind people, as previously noted, are highly heterogeneous; as Schröder-Butterfill and Marianti (2006:15) observe, the experience of vulnerability 'is not invariable even among narrowly-defined risk groups'. Nonetheless, this review found no primary studies specifically examining the experience of vulnerability of particular groups of deafblind people. While some practitioner authored material and organisational knowledge considers the factors contributing to deafblind people's vulnerability, this material is principally concerned with congenitally deafblind people and those with additional intellectual impairment. Findings from the literature cannot therefore be generalised across the highly diverse deafblind population.

As described in Chapter One (see section 1.4.1), the disability movement is critical of this etic approach to vulnerability. Rejecting the dominant construction of vulnerability as pertaining to particular groups, many maintain that vulnerability is universal, and argue that all human beings are vulnerable at some points in their lives (Grundy 2006, Hoffmaster 2006, Harrison 2008, Satz 2008, Wiles 2011). The universality of vulnerability is a core assumption of an emic perspective. It is also a key premise of the theory of vulnerability developed by Martha Fineman (Fineman, 2008, 2012), as is the notion that vulnerability is constant. Applying this theory to the experiences of people with impairments, Satz (2008:532) claims that 'vulnerability does not end when one leaves a movie theatre, a workplace, or a commuter train'. Gerontological and intellectual impairment research suggests that some health and social care practitioners conceptualise vulnerability in older and learning disabled people as constant, or as a permanent and fixed state (Grenier 2004, Parley 2010, Abley et al. 2011). Conversely, older and disabled people themselves reject this notion of being 'vulnerable in general', and refer to feeling vulnerable in specific, time-limited situations (Parley 2010, Abley et al. 2011, Wiles 2011). Comparably, this review shows that deafblind people do not describe themselves as being at risk, or feeling vulnerable, as a permanent state: 'I feel vulnerable because I am deafblind'. Instead, they refer to particular time-limited situations, such as social occasions, being alone or being in contact with health services. Therefore, like other groups, deafblind people may more accurately 'be classified and declassified as vulnerable throughout their lifespan' (Fanning and Dalrymple 2011:175).

Constructions of vulnerability focused on individuals' inherent characteristics, including the presence of sensory impairment (Greenfields et al. 2011), have influenced English social welfare law and policy (see Chapter One, section 1.4.2), and legitimated intervention by health and social care professionals (Spiers 2000). A link between deafblindness, as an inherent impairment characteristic, and vulnerability is evident in the literature reviewed, with attention paid to the relationship between difficulties communicating, accessing information and mobilising, and vulnerability. However, vulnerability is also associated with situational and external factors, such as social isolation, inaccessible services, inadequate communication support and misdiagnosis. This reflects more contemporary conceptualisations of vulnerability, which highlight not only the complex and multiplicity of environmental factors that can contribute to vulnerability (Schröder-Butterfill and Marianti 2006, Fineman 2008, Kohn 2014), but also its social construction (Gill 2006, Brocklehurst and Laurenson 2008). Deafblind people, particularly older deafblind people, describe feeling vulnerable because of unavailable, inaccessible and inappropriate care and support services. Adopting the taxonomy of vulnerability developed by Mackenzie, Rogers and Dodds (see Chapter One, section 1.4.1), such vulnerability could be considered 'pathogenic': vulnerability is exacerbated because of failures in policy and social support. The experience of vulnerability is actively constructed through the failure of society and the environment to respond adequately to both the inherent and the situational (Simcock 2017b).

As described in Chapter One, more nuanced understandings of vulnerability, combining the inherent and situational, are changing the approaches to the phenomenon that are adopted in the legal and political sphere, and within research communities. Nonetheless, the subjective, lived experience of 'being vulnerable' remains largely absent. Material included in this review pays less attention to the experience of vulnerability from the deafblind individuals' own perspectives, and the personal accounts are limited in detail and depth. Dunn et al. (2008) and Fawcett (2009) contend that it is essential for health and social care practitioners to have an understanding of the subjective lived experience of vulnerability. Failure to consider such perspectives, they argue, risks disempowering individuals, and leads to interventions that may override their wishes and priorities; physical safety in particular may be privileged over other desired outcomes. Parley (2010:267) observes that in health and social care settings, vulnerability 'generally means open to exposure to harm'; therefore interventions focus on preventing harm (Fawcett 2009). However, Kohn (2014) notes that some people may place greater priority on maintaining independence than safety. While deafblind people describe feeling vulnerable to specific harms, this review highlights that they are also concerned about lack of control, being perceived as incompetent or pathetic, being in social situations where communication is difficult, and being overprotected. In increasingly personalised health and social care systems, Abley et al. (2011) argue that practitioners must be alert to such concerns, using them to guide intervention, in order to promote person-centred care and support.

The material included in this review largely relates to negative outcomes: being at risk of abuse, poor physical health outcomes, mental ill health, ontological insecurity and social isolation. Consequently, it may perpetuate 'pervasive social norms that vulnerability is weakness' (Wiles 2011:579). Highlighting that people are rarely 'passively subject to threat', Schröder-Butterfill and Marianti (2006:10) give coping capacity equal weight as constituent part of their framework for understanding vulnerability (see Chapter One, section 1.4.1). Recognising the ability to withstand or cope with challenge as an attribute of an emic perspective of vulnerability, Spiers (2000:719) similarly observes that:

> … unless [people] perceive that some aspect of their self is threatened and they do not have the capacity to respond to the threat, they do not experience vulnerability.

Grundy (2006) maintains that family relationships, social networks, and financial assets all support older people's coping capacity. Deafblind people describe their coping capacity with reference to their ability to adapt to changes in impairment, family support, peer support and specialist services such as interpreters and communicator-guides (Simcock 2017b). Awareness of such coping strategies can inform health and social care intervention, such that services are aimed at 'bolstering people's defences' (Schröder-Butterfill and Marianti 2006:11). Although Sauerburger (1993) reports that many of her deafblind service-users showed great courage in facing various challenges over the life course, this review identifies that there is significantly less exploration of capacity to cope and resilience in the deafblind literature than the attention paid to negative outcomes. Kyle and Barnett (2012) argue that the focus on risk, insecurity and vulnerability to unfavourable outcomes continues to support a stereotyped view of deafblind people as a dependent population. The review findings appear to reflect Danermark and Möller's (2008:S121) assertion that what is absent:

> … in the scientific literature on deafblindness is a salutogenesis perspective, i.e. research demonstrating the potentiality among people with deafblindness.

Wiles (2011) highlights that vulnerability itself is not inherently negative and more positive definitions of the phenomenon have developed in the last decade (see Chapter One, section 1.4.1). Such conceptualisations maintain that it is the willingness to be vulnerable that acts as the basis and catalyst for courage (Brown 2013) and it is argued that much can be learned about resilience 'from those who have the courage to engage with their vulnerability' (Wiles 2011:574). Further exploration of the experiences of those ageing with deafblindness needs to move away from a sole focus on objective assessments of risk, threat and harm, and examine coping capacity and the potential positive outcomes experienced when vulnerability is embraced.

2.9 Conclusion

This chapter has described the method and presented the findings of a systematically conducted review of the deafblind literature. It determines what is already known about deafblind people's experiences of and views on old age and ageing, and what is known about their vulnerability. Although a rigorous and systematic search found no primary studies focused solely and specifically on these topics, some studies in which deafblind participants describe their perspectives were identified. Practitioner authored material, user testimony and organisational knowledge on these topics were also discovered. This material is very diverse in nature, in both form and content. It concerns different sub-groups of the deafblind population and, as similarly identified in Wittich et al's (2013) systematic review of the clinical and research literature in the field, makes use of different definitions of deafblindness. The primary studies adopt different approaches, and methodological limitations are evident. These limitations, the diversity of material and oft lack of clarity in relation to the particular group of deafblind people concerned rendered the use of rigorous criteria at the quality appraisal stage problematic: it would have inevitably resulted in the inclusion of such a limited amount of material that any synthesis would have been meaningless. Relevance was therefore given priority over quality and critique of the material incorporated within the review. Study limitations, the diversity of material and oft lack of clarity in relation to the particular group of deafblind people concerned also problematised synthesis of the material. Therefore, this review has its own limitations and the findings must be interpreted with caution.

Older people ageing with deafblindness are an under-studied population, receiving little attention in the literature; this reflects the dearth of research on those ageing with a range of impairments. The research gaps are thus immediately evident. The review highlights similarities in experience between those ageing with deafblindness and those ageing with other impairments: ongoing change and the resultant need for enduring adaptation; a particular relationship between ageing and impairment, with one exacerbating the other; a sense that although one can learn adaptive strategies having lived with impairment for a long time, it does not necessarily get easier; and a particular relationship with care and support services. These experiences are illustrative of the unique nature of ageing with impairment, and challenge gerontologists to engage in further research and theorising in the field of disability in later life.

The vulnerability of deafblind people may be considered axiomatic, and the etic perspective of vulnerability evident in the literature supports such a notion. Deafblind people are identified as a group more at risk than the non-deafblind majority to a range of harms. Nevertheless, the limited literature focusing specifically on the reasons for this vulnerability largely concerns particular sub-sections of the deafblind population and does not specifically consider the vulnerability of older people who have aged with the condition. Deafblind people do however describe their lived experiences of feeling vulnerable. These experiences are often related to specific situations, such as being alone, being perceived by others as incompetent, or being in social situations where communication is challenging; deafblind people do not appear to describe themselves as vulnerable simply because they are deafblind. What appears particularly limited in the literature is research adopting a salutogenesis perspective, in which consideration is given to the coping capacities of deafblind people. Further exploration of the lived experiences of the range of people who can be considered deafblind needs to move away from a sole focus on risk and harm, and explore coping capacity and the potential positive outcomes of being vulnerable.

CHAPTER THREE - METHODOLOGICAL FOUNDATIONS OF THE STUDY

3.1 Introduction

Providing a detailed account of both the methods adopted within a research study and a rationale for their choice offers an important contribution to establishing the credibility of the findings (White et al. 2014). Having outlined the literature review method in Chapter Two, this first of three methods chapters describes how and why I came to use interpretative phenomenological analysis (IPA) as my research approach. Beginning with an overview of my epistemological and ontological position, I then outline my rationale for adopting a qualitative method of inquiry and describe the theoretical foundations of IPA. Qualitative inquiry, especially that concerning sensitive topics with 'vulnerable groups', raises particular ethical concerns (Liamputtong 2007, Padgett 2008). My approach to identifying and exploring the ethical matters inherent in this study forms the next section of the chapter, which concludes by offering a detailed description of my chosen methods of sampling and participant recruitment. Throughout the research process, I kept a reflective diary; extracts from this diary are included in the following three chapters to illustrate the points made.

3.2 Foundations: Epistemology and Ontology

My epistemological and ontological position provided a grounding for the primary and secondary research questions (Smith et al. 2009) and guided the direction of the study (Creswell 1994, Groenewald 2004, Ryen 2008). The research is couched in a constructivist/interpretivist epistemology, based on an ontological position at neither end of the realist-relativist spectrum, but combined. Based on this position I reject the notion of a single external reality, intrinsic in positivist research, and acknowledge the existence of multiple realities, which people actively construct through a process of interpretation of their experiences within their social context (Ormston et al. 2014). People's experiences are therefore a meaningful source of knowledge, worth exploring (Byrne 2012, Evans 2017a); however, the research process itself is not objective and will therefore affect reality, as researcher and participants co-construct meanings and understanding (Ormston et al. 2014).

Guided by my epistemological and ontological position, the research is grounded on a series of assumptions. First, that it is important to explore people's experiences and views from their point of view, in the context of their own lives. Secondly, deafblindness, vulnerability and ageing are phenomena that are considered to be experienced differently by different people; they are significant experiences which people will seek to make sense of and reflect upon, thereby actively creating their own reality. It is not possible to gain direct access to the life world of an individual, but their telling of their experiences provides data that can inform the researcher about their involvement in the social world. Researchers therefore need to attend closely to the participants' accounts and engage in interpretative activity to develop understanding; meaning and knowledge are co-constructed by researcher and participant, as the researcher makes sense of the participant making sense of their experiences.

3.3 Research Design and Approach: Interpretative Phenomenological Analysis

I adopted a qualitative rather than quantitative approach for this study, a decision reflecting my epistemological and ontological position, and one driven by the research questions. Principally inductive rather than deductive in approach (Harding 2013), qualitative methods challenge the notion of an objective single reality and stress the importance of subjective meanings (Padgett 2008). As such, they are especially suited to studies exploring lived experiences, attitudes, opinions and behaviours, from the perspective of the participants (Padgett 2008, Byrne 2012). Qualitative approaches are also appropriate for studies of areas about which little is understood (Padgett 2008, Ritchie and Ormston 2014) and those on sensitive topics (Padgett 2008). Ungar and Nicholl (2002) argue that qualitative research and human services share an aim in giving voice to marginalised populations; qualitative inquiry also has the potential to challenge the status quo (Shaw and Gould 2001, Padgett 2008). It is perhaps unsurprising therefore that qualitative research methods have been adopted by many social work researchers (Dominelli and Holloway 2008, Taylor et al. 2015) and that there have been calls for more qualitative research exploring the experiences of the deafblind population (Jaiswal et al. 2018).

3.3.1 Choosing Interpretative Phenomenological Analysis (IPA)

As inductive methods of inquiry, I considered both grounded theory and interpretative phenomenological analysis (IPA) as possible approaches for this study. Smith et al. (2009:202) argue that there is 'considerable overlap' in what these approaches offer, and both were congruent with my epistemological and ontological position. Nevertheless, there were positive reasons for choosing IPA. Grounded theory emphasises the generation of theoretical-level accounts and conceptual explanations of particular phenomena, ordinarily based on relatively large samples (Glaser and Strauss 1967). I was interested in the more detailed and nuanced analysis of lived experience offered by IPA, which would highlight variation between participants (Smith et al. 2009). This was particularly important in this study on two grounds: there is a paucity of research on the topic, and previous studies with deafblind people have been critiqued for homogenising the population (Smith 1993, Dammeyer 2015). Furthermore, Griffin and May (2012:448) maintain that IPA's detailed attention to the experiences of marginalised groups can challenge 'prevailing assumptions that others may make about them'. Chapter Two identified that bold statements are made about the vulnerability of deafblind people, with limited empirical evidence to support them.

IPA is fundamentally concerned with lived experiences and how people make sense of these (Shinebourne 2011). It recognises that subjective experience is always the experience of 'something' (Smith et al. 2009) and pays detailed attention to those experiences that have particular significance in people's lives (Smith et al. 2009, Pietkiewicz and Smith 2014). Because this study explored lived experiences of vulnerability and ageing, IPA was particularly suited to the research questions.

Although its origins lie in psychology (Biggerstaff and Thompson 2008), IPA is increasingly used in the sub-disciplines of psychology and the health and social sciences, particularly the applied disciplines (Larkin et al. 2006, Smith et al. 2009), including nursing (Williams et al. 2010). Its use in social work research is less developed (Houston and Mullan-Jensen 2012) but is evident (see, for example, Oke et al. 2013). Loo (2012) contends that it is especially suited to social work research, particularly research with 'vulnerable groups', owing to a shared concern, amongst both the social work profession and social work researchers, to give voice to participant perspectives and to reflexivity.

A final reason for choosing IPA reflects my position as a researcher. Brocki and Wearden (2006) note that IPA offers both a theoretical foundation and flexible research guide, and is therefore suitable for novice researchers. Although IPA has not prescribed a single standardised method (Smith et al. 2009), but rather encourages flexibility and creativity (Pietkiewicz and Smith 2014), as a novice phenomenologist and qualitative researcher, the iterative six-step process described by Smith et al. (2009) was especially useful, as outlined in the next chapter.

3.3.2 Interpretative Phenomenological Analysis: Theoretical Foundations

As an inductive approach to inquiry, IPA engages in close data analysis prior to exploring relationships between the data and existing knowledge and theory (Smith et al. 2009, Harding 2013, Pietkiewicz and Smith 2014); consideration of these relationships is guided by the emerging analysis (Smith et al. 2009). However, as a research approach, IPA has theoretical foundations itself, which draw on long-standing concepts and ideas about the philosophy of knowledge: phenomenology; hermeneutics; and idiography (Shinebourne 2011). Smith et al. (2009:6) argue that it is important to be aware of these philosophical theories, in order to appreciate the 'spirit and sensibility of IPA'. I now offer a brief outline of each of these theories and their relationship with IPA; further detail can be found in Smith et al. (2009) and the philosophical literature.

Phenomenology

Phenomenology is the philosophical study of experience. The ideas of the key phenomenological philosophers, Husserl, Heidegger, Merleau-Ponty and Sartre, have all informed IPA (Larkin et al. 2006, Shinebourne 2011); the approach is considered phenomenological because it focuses on experience in its own terms (Smith et al. 2009). Highlighting the importance of experience, Husserl argues that researchers must 'go back to the things themselves' (Smith et al. 2009). Here he is challenging the human propensity to categorise things into pre-existing systems and arguing that they should be explored in their own right (Smith et al. 2009). Husserl suggests that this could only be achieved by 'bracketing' one's preconceptions or taken-for-granted view of reality and focusing on our perceptions (Larkin et al. 2006, Padgett 2008, Smith et al. 2009).

Developing Husserl's work, his student Heidegger saw people as 'being-in-the-world' (Griffin and May 2012). He describes this 'being-in-the-world', or *dasein*, as an active process, in which human beings seek meaning based on their experiences and uniquely situated perspective (Griffin and May 2012): the world appears to us, and takes on meaning, through the objects, activities, and relationships in which we are involved (Smith et al. 2009). As such, interpreting how people make meaning of their experiences is fundamental to IPA (Smith et al. 2009). Merleau-Ponty and Sartre developed these ideas, exploring both the embodied nature of our relatedness to the world and our relationships with others, and how these shape our perceptions of the world (Sartre 1956, Merleau-Ponty 1962, Moran 2000, Larkin et al. 2006). IPA therefore understands experience to be:

> … a lived process, an unfurling of perspectives and meanings, which are unique to the person's embodied and situated relationship to the world (Smith et al. 2009:21).

Hermeneutics

Hermeneutics, or the theory of interpretation, is the second theoretical foundation of IPA (Smith et al. 2009). Three hermeneutic theorists have had an influence on its development, Schleiermacher, Heidegger and Gadamer; and two key ideas are central to the IPA approach: the 'double hermeneutic' and the 'hermeneutic circle' (Larkin et al. 2006, Smith et al. 2009, Griffin and May 2012). Schleiermacher (1998) defines interpretation as a skilled craft, which draws on intuition. Challenging the possibility of knowledge outside interpretation, Heidegger views it as the means of access to 'lived time and engagement' (Smith et al. 2009:23). He examines the relationship between interpretation and pre-existing conceptions, suggesting that Husserl's requirement of 'bracketing', or the putting aside of one's own values, assumptions and preconceptions

(Ahern 1999), can only ever be achieved in part (Larkin et al. 2006, Smith et al. 2009). Heidegger argues that the analyst 'cannot help but look at any new stimulus in *the light of their own prior experience* (Smith et al. 2009: 25; my emphasis). Nonetheless, although he acknowledges the ever presence of preconceptions, Heidegger views these as potential obstacles to interpretation, and suggests that priority be given to the experience being analysed (Larkin et al. 2006, Shinebourne 2011, Smith et al. 2009). Gadamer also acknowledges the inevitable presence of preconceptions and their potential to be an obstacle to interpretation, but argues that the nature of these preconceptions may only become fully known once the analyst is engaged in the interpretative act (Smith et al. 2009).

Informed by the theoretical insights of hermeneutics, IPA recognises the interpretative role of both the participant and the analyst (Biggerstaff and Thompson 2008, Shinebourne 2011). The analyst seeks to interpret, or make sense of, the participant's interpretation of his or her experience: the 'double hermeneutic' (Smith et al. 2009). In undertaking the interpretation, the researcher engages in an iterative rather than linear process of analysis (Shinebourne 2011). Although influenced by their own preconceptions, experiences and concerns, researchers seek to bracket these and engage closely with the participants' words, as they seek to describe and interpret their own experiences; here they move from their world to that of the participant (Smith et al. 2009). The analysis moves back and forth, as the meanings of the participant are interpreted, until researchers return to their own perspective, which is now transformed as a result of engaging with the participant's account: the hermeneutic circle (Smith 2007).

Idiography

The third theoretical foundation of IPA is idiography, a concern for the particular (Griffin and May 2012, Smith et al. 2009). IPA studies are not concerned with generalisable explanations of phenomena at the population level (Eatough and Smith 2006, Griffin and May 2012), but rather focus on knowing 'what the experience for *this* person is like, what sense *this* particular person is making of what is happening to them (Smith et al. 2009:6; emphasis in original). Smith et al. (2009) note that the commitment to idiography is evident in two ways: (1) commitment to detailed analysis of significant depth, reflecting the complexity of human psychology; (2) focus on understanding specific experiences from the perspective of particular individuals in particular contexts. Idiography does not, however, shun generalisations; they are carefully developed, by locating them in the particular (Smith et al. 2009). IPA studies identify shared themes, but also the particular variations within these themes (Smith et al. 2009, Pietkiewicz and Smith 2014).

3.4 Ethics

3.4.1 Introduction

The Health Research Authority Social Care Research Ethics Committee approved this study in January 2014 (REC Reference: 13/IEC08/0049). The Social Research Association's *Ethical Guidelines* (Social Research Association 2003) and literature on research with vulnerable populations (particularly Liamputtong 2007) informed my approach to identifying and exploring relevant ethical matters. Butler (2002:241) argues that 'the ethics of social work research must logically be at least compatible if not coterminous with the ethics of social work more generally'; as a registered social worker, my approach was also informed by the Health and Care Professions Council's *Standards of Conduct, Performance and Ethics* (Health and Care Professions Council 2008) and the British Association of Social Workers' *Code of Ethics* (British Association of Social Workers 2012). The Health and Care Professions Council was the regulator of the social work profession in England at the time of data collection and analysis. Since December 2019, the regulator has been Social Work England.

I identified six key ethical matters that required consideration: voluntary informed consent; confidentiality, and the protection of participant anonymity and privacy; the discussion of distressing or upsetting topics; the potential disclosure of safeguarding concerns; recruiting participants; and disengaging from the research relationship with participants. Although these were explored during the ethical approval process, I considered and reflected upon ethical matters throughout the research process (Sinding and Aronson 2003, Liamputtong 2007); as noted by the Social Research Association

(2003:43) '[r]esearchers cannot assume that all ethical problems have been resolved when their project has been endorsed by formal ethical review'.

3.4.2 Voluntary Informed Consent

Informed consent is considered a core principle of social research (Webster et al. 2014). In its 'ethical guidelines', the Social Research Association (2003) highlights that people should only be involved in research on the basis of their voluntarily given informed consent. In order to ensure that potential participants had a full understanding of what participation in this study involved (Liamputtong 2007), I developed both a participant information sheet (see Appendix C) and consent form (see Appendix D). The participant information sheet described the study and its purpose, explained what participation involved, made it clear that people were under no obligation to be involved, and described the potential benefits and risks of taking part. Recognising that the 'clarity and comprehensibility of the information provided [is]… as important as the quantity' (Social Research Association 2003:28), I amended the participant information sheet on the basis of recommendations from the Ethics Committee and ensured that it was available in a variety of formats used by deafblind people (see section 3.5.3).

The participant information sheet was sent to those expressing an interest in being involved, and was revisited during the first meeting; participants were provided with an opportunity to ask questions, prior to commencing the interview. I then discussed the consent form; in addition to confirming consent to participate, the following areas were also covered:

- consent for interviews to be video recorded
- consent for interview data to be used for research purposes
- consent for me to be accompanied by a qualified interpreter registered with the National Registers of Communication Professionals working with Deaf and Deafblind People (NRCPD: the body that regulates communication and language professionals who work with d/Deaf and deafblind people) where necessary
- consent to use anonymised direct quotations in publications, reports and this thesis

Participant consent was explicitly recorded. For some participants this involved signing a hard copy of the consent form. For others, for whom signing a written form would have been practically and/or culturally inappropriate, their consent was recorded (verbally or in British Sign Language) on the interview video; that this had occurred was documented on the consent form. This approach to recording consent has been used in other studies with deafblind people and is recommended in guides to research with d/Deaf people (Young and Hunt 2011) and visually impaired people (Charles 2011).

Liamputtong (2007) argues that researchers must demonstrate particular sensitivity when seeking consent from 'vulnerable' groups, reflecting concerns that 'relatively powerless groups… may view researchers as… individuals who seem nice people and deserving of trust' (Wiles 2006:295) and fears that gatekeepers may explicitly or implicitly persuade people to take part (Padgett 2008, Webster et al. 2014, Poland and Birt 2018). I therefore adopted a 'process consent' approach (Munhall 1991, Poland and Birt 2018). This involved revisiting consent at the beginning of each subsequent interview and offering 'exit strategies' for participants when particularly sensitive topics were being discussed. Although such an approach has been considered reassuring for participants (Cutcliffe and Ramcharan 2002), Ali and Kelly (2012) warn against adopting a simplistic view of what may disempower 'vulnerable' research participants. In this study, I observed that not all participants appeared to need or appreciate the 'process consent' approach, as illustrated in the following extracts from my reflective diary:

I talk through the consent form again and [participant] remarks on her familiarity with these, particularly the comments around abuse and harm.

Extract from Reflective Diary: 07/07/2016

*Once the equipment is set up, I start to go through the consent form again, before beginning the second interview: part of the process consent approach. [Participant] was noticeably frustrated at this, as she commented I could go through it 'if **I** needed to': her facial expression suggests she is thinking 'do you have to go through this again?'. I wonder if [participant] is thinking, 'I've agreed to take part, I know what is involved, I don't need it explaining, I don't need protecting'. [Participant] is not the only participant to express this… The ethics procedures label [participant] as vulnerable. It's interesting that this 'being rendered vulnerable' by others becomes a topic in the ensuing interview.*

Extract from Reflective Diary: 30/05/2016

3.4.3 Protection of Confidentiality, Anonymity and Privacy

Liamputtong (2007) contends that researchers working with vulnerable people must pay particular attention to matters of confidentiality, privacy and anonymity. This involves appropriate data handling during the course of the research (Ali and Kelly 2012) in line with the Data Protection Act 1998 (replaced by the General Data Protection Regulation in 2018) and the Human Rights Act 1998, something that the Social Research Association (2003) argues is increasingly challenging in the context of new computer technologies. I transferred the video files of interviews from the recording equipment onto an encrypted and password-protected USB flash drive as soon as practically possible following the interview. I stored paper documents containing personal data, such as signed consent forms, in lockable cabinets, and electronic documents, such as those containing participants' contact details, were stored on the password-protected USB flash drive. I labelled the interview transcripts using pseudonyms and the 'key' linking the pseudonyms with personal data was stored on the password-protected USB flash drive, in a file separate to that of both the personal data and transcripts.

The Social Research Association (2003) states that confidentiality should be explained clearly in the informed consent information. Explicit reference to confidentiality was therefore made in the consent form and I discussed the topic with participants as part of the consent process before commencing the interviews; this included outlining the limitations to confidentiality as described in section 3.4.5 below. Young and Hunt (2011) observe that concepts such as consent may be unfamiliar to Deaf people, who are exposed to what Pollard (2002) terms a 'low fund of information': an experience also common to deafblind people, owing to the challenges the impairment poses to accessing information (Kiekopf 2007). In addition to meeting participants' language and communication preferences, Young and Hunt (2011) recommend adopting a conversational approach with Deaf people, to ensure such concepts are understood. Such an approach was necessary when exploring the concept of confidentiality with one of the participants in this study:

[G]oing through the consent form again, [participant] commented on confidentiality, stating, 'is this like when I talk to the doctor?' This [discussion] ...proved a useful mechanism for exploring the concept.

Extract from Reflective Diary: 22/12/2014

The protection of anonymity and privacy also involves taking steps to prevent the identification of participants, including addressing the potential that others may infer identity from any information included in the data or subsequent written thesis and publications (Social Research Association 2003). Participants' real names are neither used in this thesis, nor in associated publications, but rather replaced with pseudonyms; all direct quotations from participants are anonymised using these pseudonyms. Where in the course of the interviews participants referred to other members of the deafblind community, family, friends, professionals and support staff, or organisations, these names have also been anonymised. Notwithstanding this approach, Byrne (2012) maintains that safeguarding anonymity can be challenging when working with in-depth biographical data; it is further problematised when working with participants from small populations (Liamputtong 2007, Ali and Kelly 2012), such as the deafblind community. While there have been calls for researchers working with deafblind participants to be more explicit and detailed in their descriptions of the study population (Smith 1993, Dammeyer 2015), similar to Arndt (2010b) in her study involving deafblind college students as participants, I have omitted some biographical details of the participants in order to maintain their anonymity.

3.4.4 Distressing or Upsetting Topics

Securing informed voluntary consent and protecting confidentiality, anonymity and privacy, do not 'absolve the social researcher from an obligation to protect the subject as far as possible against the potentially harmful effects of participating' (Social Research Association 2003:35); this includes physical, psychological, emotional and social harms (Johnson and Rowlands 2012). Although there was no risk of physical harm in this study, interview-based research on sensitive topics can cause psychological and emotional distress (Guillemin and Gillam 2004, Dickson-Swift et al. 2007). It was important to be mindful that upsetting or distressing topics may arise during interviews and to identify clear strategies to manage such situations (Liamputtong 2007).

Throughout the course of the interviews, emotional topics were discussed; my approach to managing these interactions sensitively is described in the next chapter.

Undertaking in-depth interviews on sensitive topics can also have an emotional impact on the researcher (Dickson-Swift et al. 2007), the extent of which is often underestimated by those in the field (Liamputtong 2007). Researchers can experience distress or emotional drain as a result of being engaged in emotive discussions with vulnerable people (Liamputtong 2007), a phenomenon experienced by Schneider (2006) in her doctoral study with people acquiring deafblindness. Liamputtong (2007) recommends that researchers develop self-care strategies; for me, this included making effective use of supervision, debriefing with other researchers and peers, and drawing on my experiences of resilience and self-care as a social worker. Although I did not experience significant emotional drain, I was certainly not exempt from experiencing my research emotionally (Gilbert 2001):

> *I was looking forward to seeing this participant again, having watched the video of the first interview. I felt a connection with her in a way different to the other participants, perhaps because we shared some characteristics… I had also been very moved by her account and felt a sense of wanting to visit again 'to see how she was'. I was aware that [participant] had an active life, family and friends, and yet the first interview had left me feeling a sense of sadness.*
>
> ***Extract from Reflective Diary: 07/07/2016***

3.4.5 Potential Disclosure of Safeguarding Concerns

Owing to both the nature of the study and the research question topics, it was necessary to consider the potential for participants to disclose safeguarding concerns about either themselves or others, and to acknowledge my professional responsibilities, as a registered social worker, under the Health and Care Professions Council (2008) *Code of Conduct, Performance and Ethics.* I therefore adopted a position of 'contingent confidentiality'; I informed participants, prior to the interviews, that confidentiality would be maintained unless they informed me that they or someone they know was being or was at risk of abuse, neglect or harm. This contingent confidentiality was explained in the participant information sheet and consent form. Participants were advised that following a disclosure I would be required to share information with relevant professionals; reflecting contemporary policy approaches to adult safeguarding (Klee and Williams 2013, Department of Health 2016), I agreed to consult with participants to determine the best way to do so. No safeguarding concerns were disclosed during the 18 interviews.

3.4.6 Recruiting Participants

Webster et al. (2014) contend that people's right to participate in research is at risk of being overshadowed by ethical approaches that focus specifically on protection. Arguing that this right should carefully be considered, they note that '[e]thical qualitative research includes diverse views, and not just the easiest to reach' (*ibid.:*103). Recruitment of older deafblind people, who have been identified as a 'hard-to-reach' group (Kyle and Barnett 2012, Evans 2017a), was therefore both a practical and ethical matter. The strategies I adopted to recruit participants are described in section 3.5.3**.**

3.4.7 Disengaging from the Field

Finlay (2012) highlights the relational rather than procedural nature of ethical challenges arising from interview-based research. As this study involved undertaking in-depth interviews on sensitive topics, which necessitate rapport and relationship building (Harding 2013), I had to consider the potential for participants to be reluctant to end their involvement (Russell 1999, Liamputtong 2007, Poland and Birt 2018). The difficulties associated with deafblindness can lead to profound social isolation (Bodsworth et al. 2011) and many deafblind people have limited social networks (Mar 1993). I therefore had to pay careful attention to 'boundary maintenance' (Padgett 2008:77), drawing on my professional experience to explain boundaries and withdraw from researcher-participant relationships appropriately but tactfully.

Although all participants expressed an interest in being informed about the outcome of the study, and some maintained brief contact after the interviews via e-mail, no difficulties relating to participant disengagement were encountered. However, prior to the fieldwork, I had not considered my own potential reactions to disengaging from participants. Burr (1995:177) recognises that researchers may experience an 'on-going feeling of concern for the fate of each person', as illustrated in this reflection following the second interview with Rose:

> *I am struck by my feelings on leaving. Spending this time with [participant], hearing very personal stories on and off camera, and then noting that I will not be visiting again, that our 'relationship' is not ongoing. I had imagined I would be familiar with 'endings', drawing on my professional life as a social worker, but am struck by the difference – by the lack of professional boundaries, which give a framework for disengagement. I had considered disengagement in the ethical approval process, but had I considered participant disengagement from me? Again I am aware of the active life [participant] has, but her comments about enjoying company and not liking being alone, make leaving harder. [Participant] asks me if I would like another drink as I inform her that it was time to leave, but I decline. She shows me to the door, and as I head to the car, she engages in conversation with the neighbour mowing her lawn – a neighbour she describes as marvellous. As they engage in conversation, I am content to leave. She is not alone.*
>
> ***Extract from Reflective Diary: 07/07/2016***

3.5 Participants: Sampling and Recruitment

3.5.1 Sampling Strategy

Young and Temple (2014) contend that the way in which a sample is defined and determined has implications for the relevance and strength of research findings; it is important therefore to offer an outline of my approach to this process. I used purposive sampling, a form of non-probability sampling in qualitative inquiry (Ritchie et al. 2014). Described as 'the most important kind of non-probability sampling' (Groenewald 2004:45), purposive sampling involves selecting a sample with particular characteristics that will offer the researcher insight into the phenomena being studied (Padgett 2008, Smith et al. 2009, Harding 2013). Such an approach is epistemologically and theoretically consistent with IPA (Smith et al. 2009, Shinebourne 2011); the aim is not generalisation, and therefore symbolic representation rather than statistical representation is the core consideration (Ritchie et al. 2014). This does not necessarily mean that participants represent the voices or 'speak on behalf of' the wider population, albeit that their experiences may be of relevance to others (Young and Temple 2014); the sample 'represent a perspective, rather than a population' (Smith et al. 2009:49). In this study, the perspective sought was that of older people ageing with deafblindness, relating to their experiences of vulnerability and ageing.

Harding (2013) suggests that such deliberate selection risks introducing bias to the study and calls on researchers to reflect on their approach to sample choices. Epistemologically, sample selection also serves to contain 'who and what comes to be seen' (Young and Temple 2014:90). Although Iphofen (2009:109) warns researchers against the 'assumption of homogeneity' and suggests that diversity in any study population be expected, IPA studies ordinarily focus on a 'homogeneous sample'; the degree and nature of this homogeneity are influenced by the research topic and there is evidence of variation in published studies (Smith et al. 2009, Shinebourne 2011). While advising novice IPA researchers to select a fairly homogeneous group, Smith et al. (2009) acknowledge the practical and interpretative challenges in determining the boundaries of this homogeneity; such challenges became evident in this study. As Young and Temple (2014:79) identify, a 'vast heterogeneity of experience' is contained in the population described as 'deaf'. Similarly, Dammeyer (2015) reports on the significant heterogeneity of the deafblind population and its impact on research in the field; this was reflected in Chapter Two. It is important to acknowledge that such heterogeneity is not limited to varying features of the impairment; for example, deafblind people, like the general population, are diverse across, *inter alia*, age, gender, race, and sexuality domains.

In selecting particular sub-groups of the deafblind population, previous studies have focused on the aetiology of the impairment (see, for example, Damen et al. 2005, Deuce et al. 2012, Dean et al. 2017), the nature of onset (see, for example, LeJeune 2010, Dammeyer 2013, Guthrie et al. 2016a), method of communication (see, for example, Chomsky 1986, Kyle and Barnett 2012) or the presence of additional illness or impairment (see, for example, Capella-McDonnall 2005, Bodsworth et al. 2011), among other features. This study adopted a more temporal slant in relation to determining the nature of sample homogeneity, by focusing on people ageing with the impairment, irrespective of aetiology. This choice responds to the knowledge gaps and calls for further research on the experiences of this smaller sub-group, identified in the previous chapter. From my social work experience of working with deafblind people, and completing the literature review, I knew that while participants would share the experience of ageing with deafblindness, it was inevitable that they would differ in other ways. Adopting a methodology that could exploit this variability was therefore appropriate. Smith et al. (2009) argue that IPA offers an opportunity to examine psychological variability, reflecting its idiographic commitment, subject to the recruitment of a group who are homogenous in a way relevant to the study; nevertheless, it was important to be conscious of other participant differences in the analysis phase.

Table 10: Inclusion and Exclusion Criteria for Participation.

Inclusion Criteria:	**Exclusion Criteria:**
Deafblind as defined by the Department of Health (1997; 2017).	Non-deafblind or single sensory impaired
Deafblind from birth (congenital) or deafblind for the majority of adult life (acquired in childhood or early adulthood).	Has late life acquired deafblindness.
48 years of age or older.	Under 48 years of age. *
Has capacity to give informed consent to participate in the research (as defined under the Mental Capacity Act 2005).	Unable to give informed consent for himself/herself; lacks mental capacity to make a decision about participation.
Able to offer a rich and detailed first-person account of lived experience.	Unable to offer a sufficiently rich and detailed account of lived experience owing to a level of learning disability and/or mental health difficulties.
Health status is such that they are able to participate in interviews.	Acutely unwell (mentally or physically) such that they are unable to participate in interviews or where participation would be detrimental to health.
Communicates in English, Visual British Sign Language, tactile British Sign Language or via deafblind manual or block alphabet.	Communicates using language other than English, or sign language or tactile sign language from another country (i.e. not British Sign Language).
Live in England (in any setting).	Does not live in England.
Not known to the researcher in his previous role as a specialist social worker.	Known to the researcher in his previous role as a specialist social worker.

* The lower age limit was originally set at 50 years of age. One participant was 48 years old at the time he expressed an interest in taking part. This triggered a review of the inclusion-exclusion criteria and the lower age limited was amended (see section 3.5.3).

In addition to reflecting the sampling strategy, the criteria also reflect ethical considerations, for example, reference to capacity to give informed consent and current health status, while others reflect more practical concerns, for example, the availability of the requisite interpreters for those who communicate in sign language from another country. IPA analysis, like other approaches to qualitative inquiry, requires rich and detailed data (Padgett 2008, Smith et al. 2009), and it was therefore necessary that criteria include the ability to offer this. Padgett (2008) and Liamputtong (2007) observe that stereotypical views about the ability of those with particular conditions to offer personal accounts in interviews have been challenged by the experiences of qualitative researchers. Reflecting the principles of the Mental Capacity Act 2005, those expressing an interest in the study were not therefore excluded on the basis of a diagnostic label alone: I met all identified potential participants to determine both mental capacity to consent and the ability to offer detailed first-person accounts. I had concerns about the physical health status and capacity to consent of only one potentially interested person; I was also unsure if she would be able to offer a coherent first-person account. However, as Poland and Birt (2018:386) maintain, it was important that the need to 'protect vulnerable people [did] not forestall such people's… inclusion in research'; such exclusion can result in negative emotions and experience (van den Hoonaard 2018). I therefore met with this person on three occasions, once alone and twice in the presence of a deafblind manual/tactile British Sign Language interpreter, in order to determine her capacity to consent to participate and to monitor her physical well-being, in consultation with her key care workers. She presented as physically unwell in each of the three meetings, and did not understand the salient elements of research participation, such as the nature and reason for the proposed interviews, even when communication was established via the interpreter. She acknowledged her current ill health, and as such, I explained that I would not be including her in the research, but thanked her for her time and interest. All others expressing an interest in the study were recruited as participants.

3.5.2 Sample Size

Sample sizes are often smaller in qualitative than quantitative research due to the need for rich data, detailed and intensive in-depth analysis, and the lack of need for statistical representation achieved by scale (Ritchie et al. 2014). IPA studies involve particularly small samples, reflecting the idiographic commitment (Smith et al. 2009). Actual sample sizes vary in published IPA studies (Williams et al. 2010) and Smith et al. (2009) offer no specific number for IPA research, including for IPA studies undertaken by doctoral students, noting that this is largely dependent on the research topic and richness of data gathered. The resources available to the researcher can also influence the sample size (Walliman 2011). In their systematic review of health psychology IPA studies, Brocki and Wearden (2006) note an ostensible developing consensus amongst researchers towards smaller sample sizes, and suggestions range from three to ten participants (Padgett 2008, Smith et al. 2009).

I sought to recruit between eight and ten participants, the higher end of the suggested size. I was not making use of a divided sample, in which the phenomenon is explored from differing perspectives (Smith et al. 2009), as I wished to remain solely focused on the views of older deafblind people. Furthermore, data from the pilot interview (see next chapter) had not been especially rich. Nonetheless, I was also aware of my status as a novice researcher and the need to undertake more than one interview with participants. Ultimately, eight participants were recruited.

3.5.3 Recruitment: A Cerebral and Social Endeavour

Ritchie et al. (2014) contend that the recruitment process must be effective to ensure a purposive sample of sufficient quality. Chapter Two asserts that people ageing with deafblindness are largely a ‘hidden’ or ‘invisible’ population. Such populations have been described as ‘hard-to-reach’ (Liamputtong 2007). Recruitment from these populations, particularly when they are considered vulnerable, can be especially challenging (Molloy 2015, Poland and Birt 2018) and is further complicated when the research topic is also considered sensitive (Liamputtong 2007). Evans (2017a) highlights challenges specifically related to the recruitment and involvement of deafblind people in research, such as language and communication needs, and previous negative interview experiences. Furthermore, Roy et al. (2018) note the absence of good practice guidance for engaging deafblind people in research.

In their review of deafblind rehabilitation and research priorities, Wittich et al. (2016) identify how, in Canada, databases and registries of deafblind people have proved useful to researchers for recruitment purposes. English local authorities have a statutory duty to maintain registers of visually impaired people (recently confirmed in s77 Care Act 2014), and this has proved useful for the recruitment to research studies of people experiencing sight loss (Charles 2011). However, as described in Chapter One, section 1.3.1, the English legal provisions relating to deafblind people are different and while the requirement on local authorities to keep a record of deafblind people in their area has been in place since 2001 (Department of Health 2001), there is evidence of inconsistent compliance, even following publication of updated guidance in 2014 (Sense 2005, Sense 2007, Sense 2010, Waheed 2016). Data protection and confidentiality matters would also render access to both these records of deafblind people, and registers of visually impaired and hearing-impaired people that could be cross-referenced, problematic. Therefore, I decided not to make use of the records or registers for recruitment purposes, nor make contact with local authorities.

Access to and recruitment of 'hard to reach' groups often require the use of various strategies (Liamputtong 2007). From their systematic review of recruitment interventions used to recruit research participants from vulnerable populations (older people included), UyBico et al. (2007) concluded that the effectiveness of a recruitment strategy is setting and population dependent. Consequently, to ascertain appropriate recruitment strategies, I identified those methods adopted in other studies with older deafblind people and in other IPA research. Combined strategies and recruitment via specialist organisations emerged as the most successful approaches. I therefore adopted the following strategies undertaken between July 2014 and February 2016.

Strategy One: Raising Awareness about the Study

I e-mailed the two major UK based charities working with and for deafblind people, introducing myself and the study, and attaching the research protocol. One organisation invited me to meet to discuss the study. I met with the Head of Research, Head of Information and Advice, and an advanced practitioner. On behalf of the organisation, they agreed to share information about the research with their members and service users who appeared to meet the inclusion criteria. I received no response from the second organisation, despite having previously volunteered with it. Further emails resulted in a telephone conversation with the Head of Policy. It is well known that organisations have the ability to deny access to participants (Dickson-Swift et al. 2007, Liamputtong 2007), particularly where there is legitimate concern for their well-being and a desire to protect them from unsolicited intrusion in their lives (Emmel et al. 2007, Liamputtong 2007, Padgett 2008, Molloy 2015). This concern was reflected in my conversation with the Head of Policy, and no further contact was received from this organisation.

Flyers, posters, leaflets and letters are often used to raise awareness about a study and seek participants (Liamputtong 2007, Padgett 2008, Ritchie et al. 2014), but it is essential that these are accessible to those in the population of interest (Harris and Roberts 2003, Ritchie et al. 2014). This is particularly pertinent where sensory impairments are concerned (Schneider 2006, Ferguson et al. 2009, Ellis and Hodges 2013a). To ensure accessibility, the flyers and the participant information sheet were produced in the following formats: standard print (Arial point 12), large print (Arial point 16), extra large print (Arial point 26), Grade 1 Braille, Grade 2 Braille, Moon (a system of embossed reading devised by William Moon in 1845), and audio CD. The print versions were also made available electronically. I also commissioned a local specialist interpreter agency to produce a filmed British Sign Language version of the participant information sheet, with colour contrasting subtitles. The signer on this film is a Deaf woman who uses BSL as her first and preferred language. The film is available at: https://vimeo.com/103472962 (Password: *petersimcock*). Although producing this material was costly, both financially and in terms of time, as similarly observed by Moore and Miller (1999) in their study involving older visually impaired people, it proved to be an important element of the recruitment process, as illustrated in this encounter with a future participant:

Conversation with potential participant. I gathered core information to determine eligibility to participate and agreed to send out the Participant Information Sheet in audio format. The potential participant seemed surprised, and advised that he was very pleased that it was available in this format.

Extract from Reflective Diary: 05/02/2015

The material I produced was sent to the specialist charitable organisation referred to above and to local organisations working with deafblind people. Padgett (2008) reports that researchers often experience situations in which organisations express confidence in accessing participants, which are not subsequently realised. The specialist organisation advised me that they had located eight potential participants; however, two months in, no participants had actually been recruited.

Strategy Two: Gatekeepers and Gateways

Described as the organisations that can enable access to participants (Crowhurst 2013), 'gatekeepers' are seen as particularly important in qualitative research involving people perceived as vulnerable (Clark 2011, Emmel et al. 2007, Sanghera and Thapar-Björkert 2008). Having already established contact with some of these organisations, I increased my communication with them and widened the number of organisations involved. Additional flyers, participant information sheets and copies of the inclusion/exclusion criteria were sent electronically and by post, and a local specialist organisation was contacted via social media (Twitter).

Crowhurst (2013) maintains that researcher-gatekeeper relationships shape participant access, yet these relationships can be challenging (Sanghera and Thapar-Björkert 2008). Part of that challenge centres on expectations, which Padgett (2008: 83) argues must be 'clearly specified'. Acknowledging that supporting my research was not, appropriately, a priority for these organisations, I began to position them as 'gateways' rather than 'gatekeepers' (Grinyer and Thomas 2012): their role was not to actively identify, screen and recruit participants, nor actively deny access, but rather to offer opportunities to provide information about the study and, by implication, endorse its credibility. This repositioning afforded me the opportunity to write a 'call for participants' in one of the organisation's publications and monthly newsletters; this proved particularly effective in opening up the possibility of direct communication with potential participants who, although known to the organisation, had not been selected by them, nor were they necessarily receiving their services. This limited the potential for bias present in studies recruiting solely via service providers (Padgett 2008, Mackie 2012).

Five participants were recruited through this activity. It is important to note that one of these participants was 48 years old at the time he expressed an interest in taking part; he was 49 years old at the point of the second interview. This triggered a review of the inclusion-exclusion criteria in relation to the lower age limit, originally set at 50 years old. Smith et al. (2009) acknowledge that recruitment challenges may necessitate criteria revision. In studies with deafblind people, recruitment of older people has been observed as challenging (Kyle and Barnett 2012) and the widening of age ranges to maximise recruitment in such studies is evident (Powell et al. 2008, Ellis and Hodges 2013a). Given this participant's proximity to the original lower age limit and the fact that all other criteria were met, the decision was taken to widen the age range to facilitate his inclusion. This change was made once approved by the Health Research Authority Social Care Research Ethics Committee (see Table 10).

Strategy Three: Existing Relationships and Participant-led Contact

Emmel et al. (2007) highlight the important role of trust in gaining access to 'hard to reach' populations. Making contact with individuals who are trusted within the target group can be a particularly effective way of facilitating recruitment, especially when the researcher is positioned positively by this individual on the basis of a pre-existing relationship (Liamputtong 2007, Sanghera and Thapar-Björkert 2008, Clark 2011, Walliman 2011). I therefore contacted professionals and deafblind individuals well known and respected in deafblind organisations and communities, and with whom I had an existing professional relationship, seeking support with the recruitment process. It is in these activities that 'the cerebral gives way to the social' (Padgett 2008:81); investing in these relationships was fruitful, as I was positioned positively to potential participants, and interpreters, resulting in co-operation leading to the recruitment of two further participants:

Hi, How are you? Attached to this email is some information about a study, which someone I know… is carrying out. I can vouch for Peter Simcock and can assure you that he and his study are both bona fide.

Email sent to potential participant by colleague well-known in deafblind community 10/02/2016

Hi… I met with a colleague this morning, Peter Simcock, who is conducting research for his PhD… For info, although Peter is now an academic, his background is firmly rooted in work with Deafblind people and he has BSL skills, so you would be working alongside someone who 'gets it' and fully understands the communication situation. And he's a nice chap – honest!

Email sent to interpreter by colleague in senior position in specialist organisation 10/07/2015

Based on her experiences of research involving adults with brain injuries, Latchem (2016) challenges the notion that recruitment is a researcher-led process. Although her work focused on adults who may lack capacity to consent (as defined under the Mental Capacity Act 2005), it resonates with the recruitment of the eighth participant in this study. Having presented the findings of the literature review at an academic conference, I was approached by a delegate expressing an academic interest in the topic of the study. Some days after the conference, this delegate emailed me requesting to be a participant in the study, should I still be recruiting. This interaction appears to reflect Latchem's (2016:7) observation that 'recruitment… and involvement between participant and researcher is more fluid and can be more participant-led than… one way'.

Strategy Four: Snowball Sampling

Snowball sampling, the process of asking recruited participants to introduce the researcher to other potential participants (Walliman 2011), is frequently used in research involving 'hard to reach' and 'invisible' populations (Liamputtong 2007, Padgett 2008) including IPA studies (Shinebourne 2011). Participants were therefore asked to share information about the research with people known to them, who met the inclusion criteria. This strategy did not result in successful recruitment, but did highlight what may have been a recruitment barrier. Carter and Bolden (2012) contend that willingness to participate in a study is preceded by self-identification as a member of the target population. One participant advised me that she suggested to a friend that he might be interested in participating, but he had been unwilling, as 'he did not like the 'V' word (vulnerability)'. Cook (2012:339) observes that the terms used in study titles may highlight 'marks of social disgrace'; in the context of a complex relationship between disabled people and the concept of the 'vulnerable adult' (see Chapter One, sections 1.4.1 and 1.4.2), it is possible that other deafblind people were reluctant to be involved in this study, if perceived as being associated with a label they may have sought to avoid.

3.5.4 A Note on Financial Incentives

There is no consensus in the qualitative research literature on the somewhat controversial matter of financial incentives for participants. Some have argued that it is essential if recruiting from 'hard to reach' populations (Liamputtong 2007), while others have deemed it inappropriate, a threat to researcher-participant trust, and a risk to rigour in research (Liamputtong 2007, UyBico et al. 2007). My decision not to offer financial incentives was informed by both balancing these risks, and the limited resources available to me as a lone researcher. However, I sought to minimise any financial cost participants would incur; for example, I travelled to their homes for interviews, where desired, rather than asking them to meet me at the University.

3.5.5 Confirming Participation

After screening individuals to confirm eligibility for participation, I sent them further details about the research, which afforded the opportunity to ask further questions, as recommended by Talmage (2012). For seven participants, this communication was direct, rather than via a service provider, and usually involved email communication. Such regular use of online communication with the participants led me to reflect on the potential of this medium as a recruitment tool in future studies with deafblind people.

Although recruitment via specialist organisations appears to be one of the most successful methods with this population, Ellis and Hodges (2013a), in their study involving adults with Usher Syndrome, found online contact through their website and Facebook page to be the most effective; this included contact from older deafblind people, who, ironically, were not eligible for inclusion in their study.

Ritchie et al. (2014:141) highlight the importance of this initial contact with recruited individuals, noting a need for reassurance, particularly as they may feel that 'they are not sufficiently expert or would have nothing to say'. Such concerns about suitability and ability were certainly evident in this study:

I've read your interview schedule and I'm still interested in participating. Vulnerability isn't a word that features hugely in my vocabulary… [P]lease don't let me waste your time as I noticed your sample number is small.

Extract from Email from Participant 10/01/15

I am looking forward to meeting you when we are able to arrange a mutually convenient date. I am aware that I will fall far short of your abilities but hope that I will be able to respond sufficiently well.

Extract from Email from Participant 16/02/16

I'm now a bit doubtful as to whether I fit the criteria for your research. I am 67 now… [but] I've only officially been deafblind for 24 years… I'd hate to waste your time!

Extract from Email from Participant 23/02/16

Direct communication prior to the research interviews provided an opportunity to reassure participants on these matters.

3.6 Conclusion

This chapter has outlined how the research approach adopted, interpretative phenomenological analysis, reflected both my ontological and epistemological position and the research questions under investigation. Congruent with this perspective, I identified the assumptions about reality and knowledge upon which the study is based.

As a qualitative approach used in social work research, I chose IPA as it is well suited to the study of lived experiences about which little is known, and can ‘give voice’ to marginalised groups. Furthermore, IPA’s detailed and nuanced approach to the study of such experiences, underpinned by phenomenology, hermeneutics and idiography, can challenge obdurate assumptions. The approach was therefore apt, as unsupported statements about the vulnerability status of deafblind people are evident in the literature; material that has also been critiqued for homogenising the deafblind population.

Qualitative inquiry on sensitive topics involving ‘vulnerable’ groups raises particular ethical concerns. I identified ethical matters that required specific consideration, both prior to commencing the study and throughout the research process. This chapter highlights how I had to make adaptations to respond to the needs of the participants as deafblind people. This included culturally and linguistically appropriate approaches to consent, use of a variety of formats for participant information, and the reduced use of biographical details to maintain anonymity.

Purposive sampling was used and I paid particular attention to determining the boundaries of an ‘homogenous sample’, responding to the reported knowledge gap and calls for further research on those ageing with deafblindness noted in Chapter Two. A variety of recruitment strategies was used to enlist eight participants. Although snowballing as a recruitment method is frequently and successfully used in research with marginalised groups, including deafblind people, it did not result in participant recruitment in this study. Relational approaches proved most successful: ‘gatekeepers’ were positioned as ‘gateways’ and enabled direct communication with those interested in the study, and I was positively positioned by professionals in the ‘deafblind world’ with whom I had prior existing professional relationships.

CHAPTER FOUR - DATA COLLECTION AND DATA ANALYSIS

4.1 Introduction

Having outlined interpretative phenomenological analysis (IPA) as my chosen research approach, this second methods chapter outlines how this approach informed my methods of data collection and analysis. In the first part, I consider why and how I used in-depth semi-structured interviews, paying particular attention to the adaptation of interviewing practice to meet the needs of older deafblind participants. Such adaptations drew on learning from my professional experiences, a pilot interview, and the limited literature on the practicalities of interviewing deafblind people. In the second part of this chapter, I explain my approach to data analysis, which followed the iterative six-step process described by Smith et al. (2009). Acknowledging that British Sign Language interpreters' contribution to the study did not end once data had been collected, I define their ongoing role, which was essential to the analysis.

4.2 Data Collection: Interviewing Older Deafblind People

4.2.1 Semi-Structured In-Depth Interviews

Interviews and focus groups are considered two core approaches for qualitative inquiry (Harding 2013, Lewis and McNaughton Nicholls 2014). Informed by the research design, topic, and the nature of data required, I adopted in-depth semi-structured interviews, which are described as 'well-established as an effective research methodology within the social and health sciences' (Tarzia et al. 2013:3). Unlike questionnaire and survey–based approaches, in-depth interviews invite participants to offer rich, detailed descriptions of their concerns, perspectives, lived experiences, and their interpretations of these events (Griffin and May 2012, Harding 2013, Yeo et al. 2014, Hessman 2018). They are the most used and arguably, one of the best methods in IPA studies (Biggerstaff and Thompson 2008, Smith et al. 2009, Griffin and May 2012). Considered particularly appropriate for research with participants considered vulnerable or which explores sensitive topics (Liamputtong 2007, Johnson and

Rowlands 2012), they have been used in various studies involving deafblind people (see, for example, Oleson and Jansbøl 2005, Schneider 2006, Göransson 2008, and Jin and Daly 2010) and studies exploring vulnerability (see, for example, Leipert and Reutter 2005, and Høy et al. 2016).

Although IPA research does employ unstructured interviewing, Smith et al. (2009) do not recommend this approach for novice researchers. Semi-structured are the most common and preferred approach in IPA (Smith et al. 2009, Pietkiewicz and Smith 2014), as they facilitate a conversational interview, in which participants can speak freely about their concerns, while also offering the researcher some structure and direction (Smith et al. 2009, Harding 2013). Tarzia et al. (2013) suggest that semi-structured interviews are an effective data collection method in research exploring sensitive topics.

I also considered the use of focus groups, which have been used in IPA studies (Smith et al. 2009, Griffin and May 2012) and research involving sensitive topics and 'vulnerable groups' (Liamputtong 2007). Referring to various studies, Liamputtong (2007:107) contends that they can be particularly effective in studies exploring vulnerability, as focus group 'interactions can… reveal vulnerabilities of some participants and when this happens, the others will share their vulnerabilities'. However, Smith et al. (2009) acknowledge the challenge of generating first-person experiential accounts in group settings. Furthermore, although focus groups have been used in research with deafblind people (see, for example, Göransson 2008, LeJeune 2010, Gullacksen et al. 2011, Ellis and Hodges 2013a), the diverse expressive and receptive language and communication preferences and geographical location of the eight participants would have problematised this approach logistically and financially, and incurred significant travel costs for participants.

4.2.2 The Practice of In-Depth Interviewing

Harris and Roberts (2003) and Platt (2012) observe a paucity of detailed information on the practicalities of interviewing in the qualitative methods literature. Although there is some material considering the particular practical issues related to interviewing specific groups (Platt 2012), detailed discussion in published studies is rare (Harris and Roberts 2003), limiting their usefulness to other researchers (Philpin et al. 2005). There are clear practical challenges in undertaking qualitative interviews with sensory impaired people, including those who are deafblind. There are guides on undertaking research with visually impaired people (for example Charles 2011) and d/Deaf people (for example Young and Hunt 2011), but there appears to be a dearth of literature on the practicalities of research interviews with deafblind people: some studies contain little to no information on the topic (see, for example, Heine and Browning 2004, Soper 2006, Göransson 2008).

Some authors do outline certain practical matters that need consideration, predominantly related to the potential communicative and linguistic barriers that may be encountered in the field. These include:

- The need for additional time during the data collection period (Kyle and Barnett 2012).
- The need to recognise both the diversity of communication methods and languages used by deafblind people and the consequent need to adapt approaches (Yoken 1979, Kyle and Barnett 2012, Hersh 2013a).
- Consideration of the involvement of interpreters with specific experience of working with deafblind people or intervenors (Oleson and Jansbøl 2005, Ellis and Hodges 2013a).
- Ensuring that deafblind people and interpreters are offered breaks during interviews, owing to the tiring nature of some communication methods (Möller 2008, Jin and Daly 2010, Hersh 2013a).
- The use of video to record interviews (Collins and Petronio 1998, Möller 2008, Schwartz 2008).

Two papers offer more detailed discussion on the practicalities. Ardnt's (2010) paper, based on her study involving 11 American deafblind college students, explores matters relating to communication, video recording and transcribing. Evans' (2017) paper, about her UK based phenomenological study of the lived experience of adults with Usher syndrome, explores the development of an approach to interviewing she terms 'Multiple Sensory Interview and Communication Methods' (MSICM).

I have substantial experience of interviewing deafblind people, based on my previous role as a specialist social worker. I drew upon this experience in interview planning. Nevertheless, the literature referred to above usefully informed this planning process, offering insight into specific issues related to research interviews with this population, as opposed to those undertaken in social work practice. As a matter of clarification, although Evans' paper was published after my data collection was completed, I was aware of the MSICM approach she had developed during this process, owing to my professional contact with her.

4.2.3 Development of the Interview Schedule

Although flexibility is an intrinsic element of an effective qualitative interview (Harding 2013), interview schedules are commonly used in IPA studies (Smith et al. 2009); as a novice researcher, I welcomed the opportunity to have a 'guide directing [me] through the interview process' (Jacob and Furgerson 2012:2). It is also argued that an interview schedule serves to reduce researcher influence during the interviews (Appleyard and Clarke 2018). In designing the schedule, I drew on recommendations made by Smith et al. (2009), making use of open and flexible questions, with associated prompts. Jacob and Furgerson (2012) maintain that starting an interview by asking a participant factual questions about their background is an effective way of securing engagement. However, Padgett (2008) warns against this, arguing that such questions risk giving an inaccurate impression of the nature of data required. Therefore, the initial question combined enquiry about demographics with an open-question tone: *Please tell me about you.* The remaining questions adopted a similar open-question format structured around the research questions (See Appendix E).

4.2.4 Learning from the Pilot Interview

Undertaking a pilot interview is considered essential, as it provides an opportunity to familiarise oneself with the schedule and identify any problems (Padgett 2008, Smith et al. 2009); Harding (2013:48) contends that this reduces the risk of generating 'flawed data'. I undertook a pilot interview in October 2014.

While rejecting the possibility of the perfect interview, reflecting the reality of interviewer mistakes (Johnson and Rowlands 2012), Smith et al. (2009:58) contend that 'a good interview is essential to IPA'. In-depth interviewing is considered demanding and requires a range of skills (Smith et al. 2009, Pietkiewicz and Smith 2014, Yeo et al. 2014), particularly interviews involving participants considered vulnerable (Liamputtong 2007). Despite my considerable experience of undertaking social work interviews with older deafblind people, research interviews require different skills to those undertaken for assessment or therapeutic purposes (Smith et al. 2009, Gubrium et al. 2012), and, like other social work researchers (see, for example, Lillrank 2002), I found interviewing much more challenging than expected:

My initial feeling is that the interview has not gone particularly well. I was more nervous than anticipated… the interview felt… somewhat awkward and I became anxious that the level of data was 'not sufficient' (what does this mean?). Moving from 'Tell me about you' to the core questions proved difficult and felt artificial. I began silently questioning whether the data was going to be rich enough, instead of actively listening to what was actually being said by [name of participant].

I was anxious not to go into 'social work assessment' mode. Interviewing as a researcher feels like a whole different ball game.

Extract from Reflective Diary 30/10/14

The pilot interview proved useful in three ways: helping to identify potential difficulties; as an initial evaluation of my qualitative interview skills and abilities; and as a springboard for exploration of strategies to enhance these.

My concern that the opening interview question may be too broad or vague was not realised. Both in the pilot and in subsequent interviews, the participants rarely needed prompting to offer full and detailed responses about their backgrounds. Nevertheless, a key concept in the research, 'vulnerability', proved to be a challenge. Yeo et al. (2014) advise avoiding questions that present as too abstract; such questions may prove too difficult for some participants (Shinebourne 2011). In the pilot interview, in response to the core question, *Please tell me what 'being vulnerable' means to you*, the participant asked '*What do you mean by that?*' Thrown by this response, I struggled to offer a definition of this complex phenomenon, in a way that would not influence or negate the participant's own perspectives. I recognised the need to be clear on the meaning of ambiguous concepts (Charles 2011). Smith et al. (2009) recommend coming at abstract research questions 'sideways', rather than asking them directly. In their study on the meanings of dignity to people in very late life, Lloyd et al. (2014) found this non-direct way of asking about the complex concept of dignity most effective. Although the core question was not always dropped, adopting this strategy in the following interviews proved productive.

The number of short responses offered by the participant in the pilot interview engendered my anxieties about gathering data that was sufficiently rich. Lillrank (2012) observes that in an initial interview encounter, short answers are not necessarily a threat to rich data, but rather an expected response when two unknown individuals first meet. However, Smith et al. (2009) suggest that some participants may require greater levels of encouragement to offer more detailed responses. I explored how I could make better use of what Arthur et al. (2014) term 'enabling techniques': strategies to elicit more detailed accounts of participants' experiences, particularly where these may be difficult to express. Their use in subsequent interviews is described later in this chapter.

The participant's short responses in the pilot interview may also reflect difficulties in thinking of examples of specific experiences 'on the spot'. In her study with people experiencing long term illness, Charmaz (2002:305) observed that 'not all experiences are… stored for ready recall'. I tended to ask supplementary questions without affording the participant sufficient time to reflect, as recommended by Smith et al. (2009); this was noted for subsequent interviews. I also decided to send the interview schedule to participants ahead of our first meeting, affording them further opportunity to reflect on past experiences rather than being asked for immediate recall. Anxious not to suggest that participants restrict their discussions to the questions listed, thus forging the possibility of overlooking topics of concern to them, I removed the written prompts and advised that the schedule was to be seen merely as a broad guide.

Padgett (2008) and Yeo et al. (2014) contend that a good interview entails maintaining a balance between offering safe space for the participant to talk freely about topics of concern to them, while steering the interview towards topics relevant to the research questions. Some of the strategies Yeo et al. (2014) suggest for the latter, namely physical gestures such as raising a hand or leaning forward, are not appropriate in interviews with deafblind people: such gestures may go unseen. Requesting that the participant remain focused on interview schedule questions would need to be communicated more directly. Nonetheless, Shinebourne (2011) and Johnson and Rowlands (2012) highlight the benefits of allowing more participant led discussions, even where these deviate from the interview schedule; Smith et al. (2009:58) observe that '[b]ecause they arise unprompted, [such discussions] may well be of particular importance to the participant'. In subsequent interviews, my relationship with the interview schedule was more flexible; being less anxious about my perceptions of the relevance of data, I became more comfortable listening to participants' experiences as led by them. This was an important learning curve: an intrinsic element of IPA interviewing is movement round the hermeneutic circle, from the researcher's world to the participant's world. Through such movement the researcher focuses on:

> … attending closely to [the] participant's words [and is therefore] more likely to park or bracket [their] own pre-existing concerns, hunches and theoretical hobby horses (Smith et al. 2009:64).

A final learning experience from the pilot interview related to video recording the interviews. Yeo et al. (2014) note that researchers should familiarise themselves with their recording equipment, ensuring they are comfortable in its use. Nevertheless, reference is not made to participants' familiarity with such devices. For many deafblind people, their personal experiences are being captured on equipment they cannot see. I had not considered this, until on commencing the pilot interview, the participant asked about the recording equipment during the consent process. He asked to hold it, and explored it with his hands, feeling both the camera and tripod. It was then, and only then, that he agreed to be filmed.

Although the pilot interview had been a valuable learning experience, I was aware that the schedule had not been piloted with deafblind people using alternative communication methods or languages; this participant used speech expressively and used his residual hearing and hearing aids to receive speech. Following all subsequent interviews I therefore included 'process notes' in each reflective diary entry and carefully reviewed the video recordings to reflect on my interview approach as recommended by Johnson and Rowlands (2012); this contributed to the development of my skills and confidence as a qualitative interviewer. As data collection is non-standardised in qualitative research, the pilot interview data was not excluded from the dataset analysed (Arthur et al. 2014).

4.2.5 Organising the Interviews

Data collection was undertaken between October 2014 and July 2016. Successful interviewing requires careful preparation and planning (Johnson and Rowlands 2012), and a key element of this involved gathering information on participants' preferred language and communication methods. Young and Temple (2014) and Evans (2017a) maintain that identifying and meeting such participant preferences are a pre-requisite for high quality research, and ensures that the data gathered are rich and accurate, thus contributing to the trustworthiness of the findings. However, Young and Hunt (2011) observe the nuanced nature of such work, critiquing the use of simple questions about 'preferred means of communication'. More detailed information, which distinguished clearly between language (for example British Sign Language) and communication method (for example deafblind manual), was therefore gathered from participants; this included information on setting and situation specific preferences, receptive and expressive communication preferences, and desired format for written information (for example, the consent form).

Arrangements were made for face-to-face interviews. Although contemporary studies suggest that one medium of interviewing 'is not inherently superior over the other' (Yeo et al. 2014:182), face-to-face interaction promotes positive researcher-participant rapport and candid participant responses (Padgett 2008). Being physically present was also a practical necessity for those using tactual methods of communication and those for whom telephone conversation was difficult or impossible. As is now common practice in qualitative inquiry (Herzog 2012), participants were invited to choose the location for the interviews; all but one chose to be interviewed at home, a setting offering the comfort, privacy and convenience suitable for in-depth interviewing (Smith et al. 2009). The other participant opted to be interviewed at the University; a private and adequately lit room was booked for this purpose and the participant was met in the building foyer.

Seven of the participants were interviewed alone. One further participant, Celia, did not wish to be seen alone; she was interviewed in the presence of her daughter. Yeo et al. (2014) recommend respecting such wishes, and, positively, Celia's daughter was able to support communication when the interpreter needed clarification. There were a few occasions when Celia struggled to think of specific examples, and her daughter reminded her of experiences that may be relevant. In their interviews with adults living with a percutaneous endoscopic gastrostomy (PEG), Philpin et al. (2005) similarly observed carers and relatives reminding participants about experiences. The researchers questioned whether such experiences were perceived as genuinely important to the participants, as they had not directly raised them without prompting. Comparable to Philpin et al. (2005), I recognised that Celia's daughter's direct contributions could not be considered a valid part of the participant's experiential account, when undertaking the analysis.

4.2.6 Facilitating Communication

Informed by the social model of disability (Oliver 1996) in their work, Harris and Roberts (2003) observe that researchers must address barriers to participation when involving participants with impairments. In this study I needed to consider physical, linguistic and communicative matters to ensure any potential barriers to effective communication were addressed. As noted earlier, participants were offered a choice regarding interview venue, and the majority took place in participants' own homes. This provided a quiet location, ideal for those using residual hearing. I paid careful attention to where I sat in relation to the participant, making appropriate use of proximity and light as necessary, and as guided by participant preferences.

Having already established language and communication preferences, I drew on a range of communicative skills developed in my social work career in undertaking the interviews: clear speech, deafblind manual and, for introductory purposes only, tactile British Sign Language. Dammeyer (2015:8) observes that communication with deafblind people can be challenging ‘even for the researcher mastering both the local oral, signed, and tactile languages’, and I was reminded that communication preference amongst deafblind people is highly individualised:

On arrival I am reminded of the nuance of effective communication with deafblind people.... [A]s we move to the conservatory and I begin to set up the equipment, [the participant] asks, “Are you speaking loudly or is that your normal voice? Are you speaking louder for me?” I respond, “Yes, I’m speaking a little louder than normal” and [she] replies, “Well please don’t, it’s too loud, I can hear your normal voice”.

Extract from Reflective Diary 30/06/16

Table 11 outlines the expressive and receptive language and communication methods used by each participant in the interviews. Use of one particular method is not fixed, but may vary dependent on environmental and situational factors. Reflecting this, in her study involving adults with Usher Syndrome, Evans (2017a) observed that capacity to alternate between communication methods was crucial. In Mike’s third interview, for example, he experienced problems with his hearing aids and it was therefore necessary, on occasions, to support and clarify my speech with deafblind manual.

Table 11: Participants’ Language and Communication Methods

Participant Pseudonym	Expressive Language and/or Communication Method used	Receptive Language and/or Communication Method used
Mike	Speech (English)	Accesses speech using residual hearing and hearing aids Deafblind Manual
Celia	British Sign Language	Tactile British Sign Language Deafblind Manual (Interpreter facilitated)
Faye	Speech (English)	Accesses speech using residual hearing and hearing aids
Matthew	Speech (English)	Accesses speech using residual hearing and hearing aids
Phillip	Speech (English)	Accesses speech using residual hearing and hearing aids
Anthony	British Sign Language	Tactile British Sign Language Deafblind Manual (Interpreter facilitated)

Rose	Speech (English)	Accesses speech using residual hearing and hearing aids
Caroline	Speech (English)	Lip-reading and accesses speech using residual hearing and hearing aids.

As seen in Table 11 two participants, Celia and Anthony, used British Sign Language expressively, and tactile British Sign Language receptively. Young and Temple (2014) note that researchers working with different languages must decide whether to draw on their own linguistic abilities or use interpreters. Although I possess British Sign Language qualifications (Level Three Certificate: Council for the Advancement of Communication with Deaf People), my skill level is neither native nor near-native fluency. Furthermore, the majority of my British Sign Language and tactile British Sign Language use has been in the context of social work settings. I did not possess sufficient linguistic skill to complete qualitative interviews on complex phenomena using British Sign Language and therefore involved interpreters in these interviews, arrangement of which was particularly challenging.

It was especially difficult to identify an interpreter with the required experience and skill in Celia's location. After some considerable time, a local specialist interpreter agency identified a British Sign Language user who was proficient in tactile British Sign Language; however, as he was Deaf himself, I also needed an English/British Sign Language interpreter to be present. Figure 4 and Figure 5 illustrate the roles of each person in the interview encounter:

Figure 4: Asking Questions

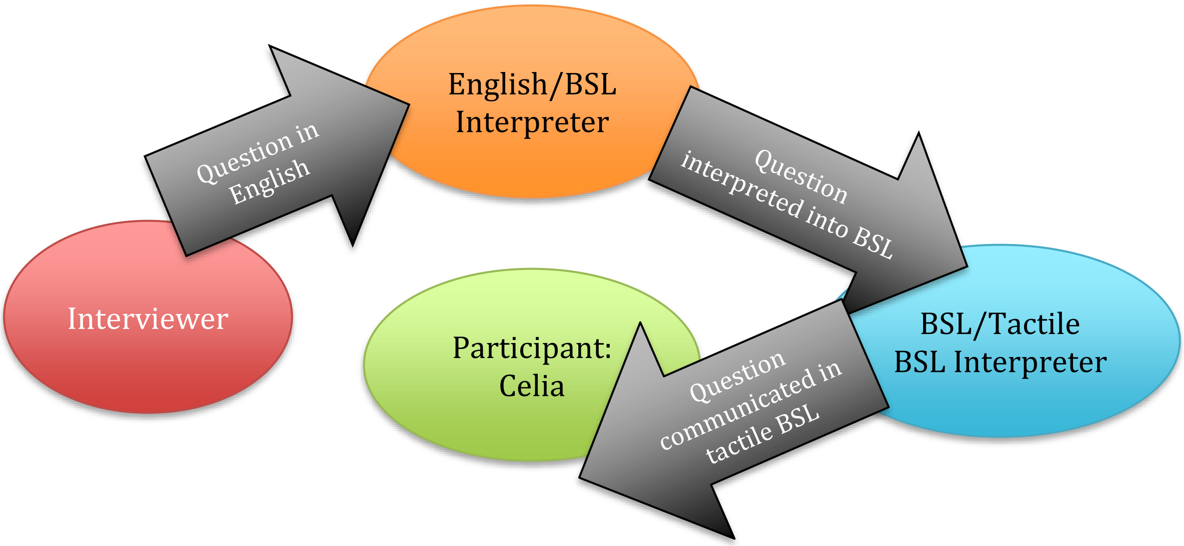
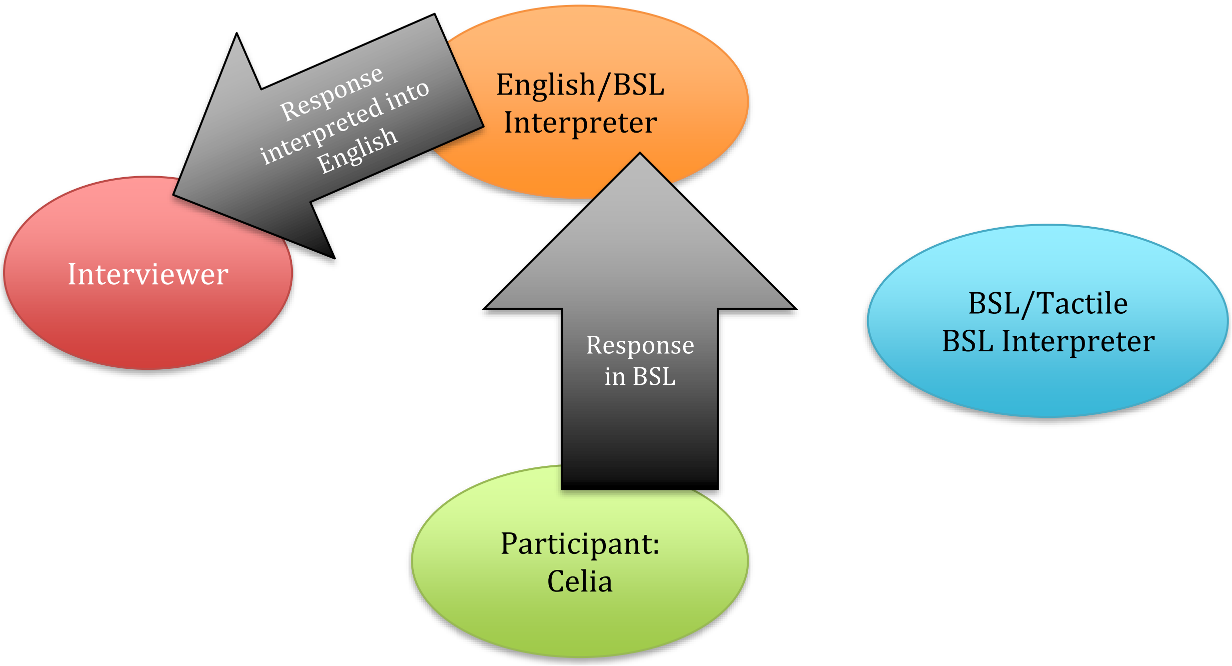


Figure 5: Receiving Responses



Although appropriately skilled and experienced interpreters were available in Anthony's location, identification of a suitable professional was rendered complex by his desire not to be interviewed in the presence of an interpreter known to him. Extensive liaison with appropriate agencies was unsuccessful in identifying someone suitable; as noted in Chapter Three, it was positive positioning of myself as researcher by a professional well-respected in the deafblind community that facilitated success.

In making recommendations for developing research grant proposals and budgets, Almalik et al. (2010) highlight the time consuming nature of arranging interviews which involve interpreters; the financial cost of such involvement is also acknowledged in the qualitative research literature (Regmi et al. 2010). For the interviews with Celia, co-ordinating a time and date convenient to all parties was especially challenging. Nonetheless, while:

> … [c]ontacting people who face barriers to participation takes time and energy as well as determination, [it] is clearly possible and *adds to the range of experiences highlighted by qualitative research'* (Harris and Roberts 2003: 14; emphasis added).

It is important to note that challenges relating to the involvement of interpreters in research, particularly interpreters of signed language, are not restricted to those of a practical nature (Young and Temple 2014). I explore the epistemological and methodological challenges in the next chapter.

I adopted a ‘passive interpreter model’: the interpreters interpreted my questions and participants’ responses, rather than conducting the interview themselves and providing me with a summary throughout, as in the active model (Almalik et al. 2010). Prior to the interviews commencing, the interpreters did engage in informal conversation to establish rapport, and to provide information on the position of those present. Akin to social work practice with individuals using a different language (Westlake and Jones 2018), Edwards (2013) observes that in cross-language research, there may be occasions when it is necessary for interpreters or researchers to rephrase questions in ways more culturally and linguistically appropriate. Almalik et al. (2010) contend that such rephrasing may be required to secure a valid response to the question posed. I was alerted to such rephrasing by the interpreters when this occurred and recorded this in the transcripts. For example:

Me: *How do you think other people see you?*
[Interpreter translates question; Anthony looks confused]
Anthony: *[vocalises] What?*
Me: *How do you think other people, what other people think about you?*
[Interpreter qualifies question by adding to it – how do you think other Deaf and Hearing people see you?]
Anthony: *When people look at me you mean?* ***(I)******
Me: *Yeah*
Anthony: *[To interpreter] – again please, explain please, ‘look at me’?* ***(I)***
[Interpreter translates question again, using sign ‘THINK’ not ‘SEE’]
Anthony: *Oh, what do they think? [Vocalised and signed] I don’t know…*

Second Interview with Anthony (32.16-33).

* As British Sign Language has no written form, (I) is used to indicate that the response is interpreted (see Chapter Five, section 5.2.6).

4.2.7 Gathering ‘Rich’ Data

In phenomenological research, Van Manen (1990:67) observes that ‘[i]nterview material that is skimpy and that lacks sufficient concreteness in the form of stories, anecdotes, examples of experiences etc. may be quite useless’. In this section, I describe the strategies used to ensure the gathering of rich data: establishing rapport and trust;

questioning style; use of enabling techniques; and the management of sensitive topics and emotion.

Establishing Rapport and Trusting Participant-Researcher Relationships

Gathering rich data in an interview is 'a highly skilled task' (Harding 2013:34), and requires the development of a positive researcher-participant relationship (Jacob and Furgerson 2012, Johnson and Rowlands 2012). Harding (2013) contends that the quality of this relationship is an indicator of the validity of the data, reflecting the view, evident from the latter decades of the twentieth century, that 'rapport rather than coolness [is] the truth-eliciting strategy' (Warren 2012:136). Establishing rapport with participants is seen as the critical first stage in developing a positive, trusting relationship (Harding 2013) and the subsequent gathering of rich data (Smith et al. 2009, Foley 2012, Warren 2012). Such rapport is particularly important in research on sensitive topics, in which participants are asked to share very personal experiences (Liamputtong 2007, Grinyer and Thomas 2012). For example, Tarzia et al. (2013), in their study of sexuality in residential care homes, found that older people were more willing to discuss the topic when a positive rapport with the researcher had been established.

Developing and maintaining rapport are not straightforward (Liamputtong 2007) and some researchers devote the entire first interview to achieving this goal (see, for example, Booth and Booth 1994). I drew on my professional social work experience and practices described in the qualitative research literature. I engaged in phatic communication, or 'small talk', prior to starting the interviews, creating a relaxed and friendly atmosphere (Johnson and Rowlands 2012, Yeo et al. 2014). To avoid what Wadsworth (1984) describe as a 'data raid' or 'smash and grab' approach, I also engaged in conversation with participants once the interview had ended and the camera had been turned off. Liamputtong (2007) suggests that this demonstrates genuine interest in the participants. To maintain rapport, I used active listening skills throughout the interviews, paying careful attention to body language and behaviour, and responding to check meaning. Liamputtong (2007:57) maintains that where rapport and a trusting relationship have been established, 'it is likely that the vulnerable participants will share their lived experiences, which they have never shared with anyone'. In one-to-one interviews, it is not known to the researcher whether the participant is sharing things that have not been shared with others. However, in the first interview with Celia, which took place in the presence of her daughter, with whom she lived, it appeared that Celia may have been disclosing thoughts and feelings not previously expressed; this suggests I had been successful in forming a trusting relationship:

Celia: *... one thing, one big thing, when I'm getting so angry, I'm waiting for my deathbed.* ***(I)***
Daughter: *Oh mother! Yes, that's what we're trying to avoid [not interpreted to Celia].*
Celia: *[uses multi-channel sign to indicate 'I don't want to talk about it] I know it's really silly but [uses multi-channel sign to mean 'damn'/'frustrating situation]* ***(I)***
Me: *Hmm hmmm*
Daughter: *Hmm hmmm. I've never... not heard any of this before. She's kept it all in [becomes tearful].*
Celia: *I think my daughter's shocked to hear that* ***(I)***

First Interview with Celia (7.25-38).

This interaction counters the contention of Murray and Wynne (2001) that in sensitive and emotive research, rapport may be better established in one to one encounters. Nevertheless, I was conscious of the presence of interpreters in five of the interviews and the challenge this may pose to researcher-participant rapport (Hessman 2018, Westlake and Jones 2018). Young and Hunt (2011) observe that in interpreted interviews, the voice over provided by the interpreter is not entirely synchronous with the signs of the participant. This disjuncture means voiced words do not match the corresponding non-manual features of the signer; Young and Hunt (2011) argue that for the non-signing researcher, this renders active, empathic listening difficult. To respond to these challenges, I engaged in direct communication with both tactile British Sign Language using participants prior to and immediately following the interviews; my level of British Sign Language was sufficient for such 'small talk'. Furthermore, I cannot be considered a 'non-signing researcher'; my skill level was not so insufficient that empathic and active listening was rendered problematic.

A further rapport developing strategy that I adopted was self-disclosure: on occasions, I shared my own experiences, ideas and feelings with participants. Whether researchers should self-disclose has been the subject of much academic debate (Foley 2012, Warren 2012). It has been argued that self-disclosure does not necessarily result in richer data (Foley 2012) and that over-identification with participants may distort their responses (Miller and Glassner 2004); in particular, participants may feel restricted to talking about those experiences they share with the researcher (Miller and Glassner 2004, Abell et al. 2006, Harding 2013). However, Johnson and Rowlands (2012:107) argue that the more traditional impersonal interviewing approach is:

> … not a realistic ideal for in-depth interviewing, because the nature of the research question itself usually entails a deeper process of mutual self-disclosure and trust building.

From the 1980s, critical and feminist researchers have used self-disclosure and encouraged reciprocity between researcher and participants in interviews, as a means to build trust and rapport (Warren 2012, Yeo et al. 2014). In research on sensitive topics in particular, Dickson-Swift et al. (2007) and Liamputtong (2007) contend that self-disclosure is essential in creating a 'level playing field' through which participants are encouraged to be open, while their experiences are respected and validated. Dunbar et al. (2002:291) refer to such self-disclosure as 'the foundation work' of a successful interview.

Warren (2012) acknowledges that the decision whether or not to self-disclose belongs to the researcher; Foley (2012) suggests that this decision depends on determining when self-disclosure would be effective in achieving the desired aim: the gathering of rich data. Therefore, my decision whether or not to self-disclose was not fixed, but flexible, depending on the situation and relevance to the topic. For example, prior to the initial interview with Anthony, he disclosed to me that he felt vulnerable in relation to questioning his own sexuality, but had difficulties explaining this. In this situation, the topic was relevant to the research and had been raised by the participant; therefore, I disclosed that I was in a same-sex relationship and had experienced the challenge of questioning and 'coming out' to myself. This appeared to open the dialogue and the topic was subsequently discussed in the interviews. When first meeting Rose we engaged in informal conversation prior to the interview, in which Rose discussed some of her religious and political perspectives on events happening at that time; my perspectives were largely similar, but in this situation I chose not to disclose, as the topic was not relevant to the research. In some situations, I offered what Johnson and Rowlands (2012:104) term 'complementary reciprocity'; this involves the sharing of information rather than disclosure of one's own experiences, ideas and thoughts. For example, on occasions I provided participants with information about support and services for deafblind people.

Questioning Style

A key feature of in-depth interviewing is the combination of structure and flexibility (Yeo et al. 2014). As recommended by Smith et al. (2009), I used the interview schedule flexibly, viewing it as a guide rather than a prescriptive tool. Questions were not always asked in the order of the schedule, but in an order that responded to the direction of the participants' responses. I used follow up questions to draw out further detail or returned to the schedule for a different question if the participant's discussions were deviating from research relevant subjects. I predominantly made use of open questions, considered the 'standard tool of in-depth interviewing' (Yeo et al. 2014:191), as these encourage participants to talk freely and in greater depth (Wang and Yan 2012). However, I also made use of closed questions to clarify specific issues and check my understanding of participant responses. Such an eclectic questioning style enabled me to move from discussion about general issues to specific experiences, as required in IPA research (Smith et al. 2009). I largely avoided leading questions, but did make use of these where specific clarification was required in relation to my understanding of the response: Yeo et al. (2014) note the value of leading questions in this context.

Padgett (2008) and Byrne (2012) suggest that qualitative interviewers should avoid unnecessarily interrupting participants, which may occur through the repetitive use of verbal interjections or other utterances (Yeo et al. 2014). Although visual signs of attentiveness and encouragement to continue, such as smiles, clear eye contact and nods are recommended (Walliman 2011, Yeo et al. 2014), such visual markers are not necessarily appropriate in interviews with deafblind participants. I had to adapt my approach, making regular use of audible interjections (for example, 'hmm hmm', 'OK', 'Yeah') when interviewing those with residual hearing, and making use of touch when interviewing those who communicated tactually, responding to the insignificance of visual cues related to turn-taking (Schwartz 2008). Similarly, while extended periods of silence are encouraged in qualitative interviews (Van Manen 1990, Talmage 2012, Pietkiewicz and Smith 2014), as providing an indicator that you wish the participant to continue talking (Smith et al. 2009), such silences had to be balanced with the need to indicate verbally or tactually that I was still listening and engaged.

Use of Enabling Techniques

Interviewers use enabling techniques to support participants in self-expression, particularly in relation to sensitive topics, while also encouraging them to offer more detail and depth in their discussions (Arthur et al. 2014). I made use of case examples, probes and prompts. Use of case examples is particularly useful in guiding the participant from the general to the specific (Smith et al. 2009, Arthur et al. 2014); this usually involves asking the participant to offer specific examples of experiences (Van Manen 1990), as illustrated in these extracts from my transcripts:

Faye: *...sometimes you do actually worry [pause], that you know, you might hurt yourself, like I say, you might, the stairs that you don't see or falling over, and things, making a fool of yourself [nods]*

Me: *Can you think of a time or tell me about a time when you've been in those sorts of situations? Can you give me a specific example of when that's happened to you?*

Faye: *Well, I, I don't know whether this is the sort of thing you were looking for, but one of the things, experiences that came to mind...*

First Interview with Faye (7.1-11).

Me*:* *D'you have any other examples, so there was the receptionist, and I wondered if there were any other examples?*

Phillip: *[pause] There are places that don't know me, I mean the bank, my, my bank knows, knows me fairly well, so they, they would, err, kinda know that I can't see. Erm, I think in new, in new situations, erm, erm, even I'm afraid I have to say this, but coming here at [name of specialist charitable organisation], not so long ago, to attend a meeting, one of the volunteers came up to me, saw I had a white stick, and said, erm, 'OK, my name's [name], hello, nice, pleased to meet you', and said, 'Can you follow me?' Didn't offer the arm or anything, I just waited there [pause], and waited.*

Second Interview with Phillip (27.6-16).

I also made use of probes in the interviews, an enabling technique considered particularly useful in achieving rich data (Padgett 2008, Smith et al. 2009, Talmage 2012), and to a lesser extent, prompts, in which participants were asked to comment on a particular perspective or idea (Yeo et al. 2014); for example, I asked participants their views on the description of deafblind people as one of the most vulnerable populations. Some probes were written into the interview schedule; others were used in response to participants' answers, and included asking them to 'tell me more about that' or asking how particular situations made them feel.

Smith et al. (2009) suggest that attempting to 'expose the obvious' can be a useful way of moving beyond what 'you think you already understand'. I found this to be a particularly effective form of probing and, as noted by Enosh et al. (2008) and Johnson and Rowlands (2012), it is a useful way to 'bracket' any common sense or taken for granted understandings:

Me: *Erm, I want to ask you, this might seem a very obvious question, but you said erm, you didn't feel safe, and you were talking about getting a chain on the door, can I ask, why didn't you feel safe?*

Celia: *If the door was open, it's a wide door and opens towards me, I am able to see, but I'm not able to see if it's not open fully. One night, someone was at the door, so I turned on the CCTV screen. There was a man standing at my door, he had his back to the CCTV camera. I didn't know who the person was and he wouldn't turn around. I was surprised. I hadn't seen him before, so I left it. A few months later my daughter came home from work with my grandson. It was him who'd been at the door. [Indicates talking to grandson] 'My goodness, I'm so sorry', he came to me and I gave him a cuddle. That door is not suitable for me. At night, I close all the doors and windows, then go to bed. I lock [emphasised by signing lock x3] everything myself. I just don't feel…* ***(I)***

First Interview with Celia (2.40-3.5).

Smith et al. (2009) observe that IPA studies offer scope for imaginative approaches to data collection. One such approach, which I had not considered due to participants being deafblind, is the use of visual materials (photographs, pictures, objects) to prompt discussion (Borer and Fontana 2012, Arthur et al. 2014). Nevertheless, Anthony introduced his visual and tactile artwork into the interviews, which facilitated deeper discussion of what may be considered abstract ideas:

Anthony: *[points to another picture] Can you feel that?* ***(I)***
[Interpreter hands picture he has been 'feeling' and explains to me the ridges and the textures to feel – interpreter explains to G that I am feeling the pictures]
Me: *So there's a lot of different colours…*
Anthony: *[vocalises] yeah*
Me: *If I asked you to paint 'being vulnerable', how would you paint it?*
Anthony: *Imagine it, imagine it.* ***(I)***
Me: *How do you imagine it?*

First interview with Anthony (11.49-12.14).

Although pre-existing concerns must be bracketed and the participants' words carefully heard (Smith et al. 2009), in her study involving adults with Usher syndrome, Evans (2017a) observed that having some relevant prior knowledge and experience encouraged participants to offer further details and maintained a sense of flow in her interviews. Like the increasing number of researchers who are exploring topics about which they have prior knowledge (Johnson and Rowlands 2012), Evans had previously worked with adults with Usher syndrome in her role as a specialist social worker. I too made use of existing knowledge, from my experience in specialist social work, in order to maintain flow and to enable the participants to focus on their experiences rather than having to explain terms.

Management of Sensitive Topics and Emotion

Padgett (2008:118) highlights that qualitative interviews on sensitive topics may bring 'emotions to the surface'. Although there was much laughter and humour in my interviews, participants also became tearful and expressed anger. I drew on my social work training and experience to create what Padgett (2008) calls a 'safe space' for the expression of these emotions. I paid careful attention to the participants' responses as the interviews progressed, and when asking emotive questions, I prefaced these with an alert that the topic was emotive and a reminder to participants that they did not need to answer if they did not wish to do so. Yeo et al. (2014) note the risk of such prefacing affecting the clarity of the question, particularly where the preface is convoluted. However, for deafblind people making use of residual hearing for receptive communication, being alerted to a topic, particularly where this has changed from the previous discussion, is considered to aid communication (Deaf First 2017).

Some topics were highly emotive; nevertheless, I was careful not to avoid them as this 'assumes that participants are incapable of handling themselves and their emotions' (Padgett 2008:118). I did not probe unnecessarily, nor challenge a participant's decision not to discuss a topic; rather, I provided space for the participant to respond further if they wished to do so. The following transcript extract illustrates this approach:

Rose:	*And I still, although I understand that now, that I know, erm, that there're other psychological reasons for that, I know all that and, and we're not going into a discussion about that, err, but at the same time, erm, I still feel fairly, feel quite ashamed of that. So therefore that's something I wouldn't, I, I don't like talking to other people about.*
Me:	*Hmm*
Rose:	*Erm, only a few of my close friends, well the people who knew me at that time know, and accepted that.*
Me:	*Yes*
Rose:	*They, I will say that, they never, ever held it against me in any way. But, erm, I don't tell anybody that I know now, unless I know them very, un-, unless I'm very sure of them and know them well enough to tell them.*

First Interview with Rose (6.28-43).

Towards the end of interviews, I moved to less emotive and more neutral topics, while also offering the participants the opportunity to offer anything not previously covered and to ask questions. Yeo et al. (2014) highlight that spending time with participants after the interview, provides an important opportunity to maintain rapport and demonstrate appreciation for their time. Once the camera had been turned off, I engaged in conversation with the participants and thanked them for their time and engagement in the interviews.

4.2.8 Duration and Number of Interviews

Gathering interview data of sufficient depth for IPA analysis is time-consuming (Smith et al. 2009, Johnson and Rowlands 2012); Warren (2012) and Yeo et al. (2014) recommend between one and one and a half hours per interview. Longer interviews can adversely affect concentration for both parties (Yeo et al. 2014), and Jacob and Furgerson (2012) observe that such interaction may be especially tiring for older people. Additional considerations in this study were the tiring nature of deafblind communication (Möller 2008, Sense 2015) and the need to offer interpreters a break (Möller 2008, National Union of British Sign Language Interpreters 2017). It was therefore necessary to balance these considerations with the need for data of adequate depth. Participants were advised of the approximate time that interviews would take in the participant information sheet, as recommended by Smith et al. (2009), and determining an appropriate time to bring the interview to a close was participant-led. Interviews lasted between 29 minutes and 97 minutes: the average interview length was 64 minutes.

Participants were interviewed more than once (see Table 12). Padgett (2008) recommends this approach in qualitative research, which offered three advantages:

- It enables the participant to bring the interview to a close if feeling tired or emotional, in the knowledge that a further interview will be happening (Earthy and Cronin 2008). This was particularly useful in interviews involving interpreters, who also needed breaks.
- It supports the development of participant-researcher trust and rapport, necessary for high quality data (Grinyer and Thomas 2012, Tarzia et al. 2013). My interaction with Rose illustrates this point. In her first interview, Rose raised a particularly emotive topic (her experience of mental ill health) but she did not wish to discuss this; in the second interview, she discussed the experience openly.
- It offers the researcher an opportunity to verify understandings and check the meanings of discussions in earlier interviews (Young et al. 2014, Johnson and Rowlands 2012) and probe for further detail and more specific examples (Grinyer and Thomas 2012, Johnson and Rowlands 2012). After each initial interview, I reviewed the video recording carefully, making notes of areas needing clarification and issues warranting further probing; this provided a prompt sheet for the subsequent interview(s).

Table 12: Number of Interviews with each Participant

Participant Pseudonym	Number of Interviews
Mike	3
Celia	2
Faye	2
Matthew	2
Phillip	2
Anthony	3
Rose	2
Caroline	2
Total:	**18**

Six participants were interviewed twice. Mike was interviewed three times; the second interview was cut short as his support worker arrived early to take him to an appointment. Anthony was interviewed on a third occasion at his request.

4.2.9 Recording the Interviews and Transcription

Audio or video recording interviews enables the researcher to attend closely to the participants' responses, rather than be distracted by contemporaneous note taking (Harding 2013, Arthur et al. 2014), and to facilitate subsequent IPA analysis (Smith et al. 2009). I video recorded all interviews using a tripod-mounted camcorder. Paying careful attention to non-verbal communication and behaviour, and the visual expression of emotion during interview interactions, can add depth to subsequent analysis (Lillrank 2012, Pietkiewicz and Smith 2014) and video recordings captured such interaction; video recording was also essential for those participants using British Sign Language expressively and tactile British Sign Language receptively (Arndt 2010b, Young et al. 2014). When video recording interviews, Arthur et al. (2014) observe the importance of appropriate camera positioning. British Sign Language does not rely solely on the hands to create meaning; its productive and established lexicon consist of five parts: hand shape, movement, location, orientation and non-manual features (facial expression and mouth/lip patterns) (Sutton-Spence and Woll 2006). It was therefore essential that I positioned the camera such that the participants' hands, faces, shoulders and upper bodies could be clearly recorded (Arndt 2010b).

As recommended by Smith et al. (2009), following each interview I wrote notes and reflections, capturing contextual information and my initial impressions of the encounter. These served as useful prompts in subsequent interviews and reminders of the interview interaction in the analysis phase.

A verbatim record of the interview is required for IPA analysis (Smith et al. 2009). Therefore, following each interview, I transferred the video recorded file from the camcorder to a password-protected USB flash drive, ready for transcribing. Transcription is time-consuming (Potter and Hepburn 2012), particularly so the transcription of signed languages (Ladd 2003, Arndt 2010b), and therefore qualitative researchers often commission a transcription service (Potter and Hepburn 2012). However, Potter and Hepburn (2012:559) contend that this can result in 'impoverished transcripts', particularly where the transcriber is trained solely as a speed typist. I was also aware that a commissioned transcriber might focus solely on the spoken words of the interpreter, where used, rather than paying careful attention to the British Sign Language used by two of the participants. I therefore transcribed all 18 interviews myself. IPA does not require highly detailed recording of the prosodic features of speech (Smith et al. 2009) such as that evident in Jeffersonian transcribing; nevertheless, as recommended by Poland (2002) and Smith et al. (2009), features such as significant pauses, hesitations, 'false starts' and laughter were included. I discuss my approach to transcribing the interviews with participants using British Sign Language in the next chapter, placing it in the context of interpretation and translation.

Although time-consuming, transcribing the interviews myself offered two advantages: it safeguarded participant anonymity and confidentiality; and it enabled me to immerse myself in the data, the first stage of IPA analysis (Smith et al. 2009). During the transcription process, I made a note of responses that particularly stood out to me, my initial thoughts on the interaction and any areas of interest, to accompany the notes made following the interviews themselves. Once complete, participants were allocated a pseudonym and saved in a different folder to the video files.

Sharing completed transcriptions with participants, a process termed 'member checking', can be a useful way to promote rigour in qualitative research (Ferguson et al. 2009), but is not practicable in all studies (Grinyer and Thomas 2012). I lacked the resources to produce transcripts in the range of formats necessary, nor was it possible to produce a written transcript that was accessible to the participants using tactile British Sign Language: this would merely be a 'back translation' of the written transcript (Young and Temple 2014). Furthermore, as noted by Schwartz (2008), video recordings of conversations with deafblind people are often inaccessible to them. I acknowledge this limitation to my study, albeit that, as noted earlier, second interviews offered an opportunity to check my understanding of the participants' meanings in the initial interviews.

4.3 Data Analysis

There are no standardised procedures for qualitative data analysis (Walliman 2011) and although various papers outlining the core stages of IPA analysis have been published (Larkin et al. 2006), the 'existing literature on analysis in IPA has not prescribed a single method for working with data' (Smith et al. 2009:79). IPA does nonetheless offer adaptable guidelines (Eatough and Smith 2006, Shinebourne 2011, Pietkiewicz and Smith 2014), which reflect the key characteristics of this approach to analysis, as outlined by Cooper et al. (2012:5):

> (a) movement from what is unique to a participant to what is shared among participants;
> (b) description of the experience which moves to an interpretation of the experience
> (c) commitment to understanding the participant's point of view; and
> (d) psychological focus on meaning-making within a particular context.

While IPA analysis welcomes flexibility and creativity (Pietkiewicz and Smith 2014), Biggerstaff and Thompson (2008) observe that the process can be daunting to the novice researcher. I therefore followed the iterative six-step process outlined by Smith et al. (2009) in their text specifically for novice IPA researchers. Throughout the analytic process, I kept a record of my thoughts, interpretations and decision-making.

IPA analysis begins by focusing on the single case, reflecting its idiographic underpinning (Smith et al. 2009). I chose to start the process by analysing Faye's experiences, as recounted over two interviews, as Smith et al. (2009:82) recommend starting with an interview that one found 'detailed, complex and engaging'. The first interview with Faye was the fifth I had undertaken, so my interviewing skills had developed at this point, resulting in very rich data. Faye's interviews were in spoken English rather than tactile British Sign Language, which enabled me to develop my confidence in the analytic process before analysing the interviews in British Sign Language.

4.3.1. Step One: Reading and Re-Reading, Watching and Re-Watching

The first analytic step involves immersing oneself in the data, to metaphorically 'step into the participants' shoes' (Pietkiewicz and Smith 2014:12) and enter their world. Completing transcriptions myself had offered an introduction to this step, which in practice involves repeated revisiting of the data (Van Manen 1990). In the majority of IPA studies, written transcripts are read and re-read (Smith et al. 2009). In this study, this step also involved watching and re-watching the videos; where the interviews had been conducted in tactile British Sign Language, the videos were also watched and re-watched with the interpreters, providing an opportunity to clarify the data (Schwartz 2008). During this 'revisiting of the data', as recommended by Smith et al. (2009), I made notes to record my recollections of the interview itself, initial observations and thoughts, and contradictions in participant responses; these notes were added to the word document on which my post-interview reflections had been written, in order to produce an ongoing record of my thoughts for each interview. I also highlighted the richer, more detailed areas of the transcripts.

Larkin et al. (2006:108) observe that 'we can never fully escape the 'preconceptions' that our world brings with it. But this should not discourage us from making the attempt'. I attended closely to the participants' responses, seeking to 'bracket' any of my own assumptions and presuppositions, viewing the data on their own terms, without the imposition of existing theoretical frameworks. Keeping notes during this process enabled me to revisit my initial thoughts during the later steps in the process; this ensured that I remained open to amending my initial perspectives.

4.3.2 Step Two: Initial Noting, Exploratory Commenting

Described as 'detailed and time-consuming' (Smith et al. 2009:83), the second analytic step is somewhat merged with the first; indeed, in their 'Practical Guide to using IPA', Pietkiewicz and Smith (2014) present these two steps as one. Following close reading of the transcript, this step involves producing detailed notes, or an exploratory commentary, in which the analyst comments on content of interest. This commentary is not written separately, but on the transcript itself (Smith et al. 2009), which ensures it is explicitly linked to the data. My commentary on the interviews undertaken in tactile British Sign Language was, therefore, like the others, recorded on the written transcript/translation, in written English; however, during this step, I contemporaneously watched the video in addition to reading the transcript, to ensure any important linguistic and cultural features were recorded in my notes. Transcripts were analysed in conjunction with this viewing of the videos.

There are various ways of recording the exploratory commentary. Some researchers have made use of computer software such as QSR NVivo (see, for example, Black 2008, Vicary et al. 2017) or the commenting function in Microsoft Word (see, for example, Cooper et al. 2012). Although video and audio recordings of interviews can now be uploaded into QSR NVivo (Young and Temple 2014) or annotating software packages used by linguistics researchers such as ANVIL and ELAN (Schwartz 2008, Hessman 2018), Smith et al. (2009) recommend writing commentaries by hand on hard copies of transcripts, arguing that computer use can distance the researcher from the data. After discussion with other IPA researchers who also recommended the use of hand written commentary on hard copies of the transcripts, I decided to adopt this approach. It enabled me to remain close to the data, and practically, made it easier to review the interview videos on the screen whilst having a printed transcript in front of me.

I printed the transcripts onto A4 paper with a landscape orientation, and recorded the exploratory comments in a wide margin (Smith et al. 2009, Griffin and May 2012). I first underlined text that appeared significant, and noted my reasons for doing so; in particular, I underlined emotive responses and those seeming distinct (Pietkiewicz and Smith 2014). To develop the exploratory commentary, I used the three analytic tools suggested by Smith et al. (2009): descriptive comments; linguistic comments; and conceptual comments. While these can be used discretely (Cooper et al. 2012), I used them in parallel; this enabled me to ensure my interpretation remained rooted in the data. As recommended by Smith et al. (2009) I used different coloured ink for each comment type.

Descriptive Comments:

My descriptive comments described the content of the interview: the key experiences, descriptions of events, explanations, and phrases used by participants. Using either words or short statements, I commented on 'what was actually being discussed' (Pietkiewicz and Smith 2014:13): the P in IPA.

Linguistic Comments:

Young and Temple (2014:145) observe that '[w]ithin interpretative and constructionist epistemologies, it matters how something is said… and using which choice of language'. Linguistic commenting involves the analyst making notes on language use by the participants (Smith et al. 2009). When undertaking linguistic commenting on the transcripts of the spoken language interviews, I commented on such features as significant pauses, repetition and hesitation, use of metaphor, laughter, tone and emphasis.

Young et al. (2014) highlight the challenges of IPA analysis involving signed languages, noting IPA's usual focus on a written transcript, and the visual and spatial features integral to grammar and meaning in British Sign Language. They note that much of what might be significant, and therefore require commenting on, would not be contained in a written transcript. With tactile British Sign Language, the tactual is an additional important dimension, albeit that both participants receiving communication tactually did not do so expressively. Therefore, when commenting linguistically on the interviews with those participants using tactile British Sign Language, it was essential to analyse the transcript in conjunction with the video. I paid careful attention to the language use of the participant, noting features such as eye gaze, multi-channel sign use, and other non-manual features. I also paid careful attention to choice of sign. For example, in the interviews with Anthony, although the term 'vulnerability' was voiced over by the interpreter, I noted that Anthony used the sign also used to mean 'weak' or 'ill'; an alternate sign for 'vulnerable' or 'vulnerability' is that which also means 'risk'. This difference was not initially recorded in the written transcript, but observed in the video; it appeared particularly significant and was therefore commented on. Padgett (2008) and Squires (2009) argue that phenomenological approaches do not work well in cross-language studies, because of the focus on use of language to describe experience. However, although supported in the interviews by an interpreter, my knowledge of British Sign Language significantly reduced my 'linguistic distance' from the data. It is important to acknowledge, nonetheless, that my commenting was in written English.

Conceptual Comments:

Conceptual commenting requires time and reflection, as the noting moves from a descriptive to an interpretative level (Smith et al. 2009): the I in IPA. Moving beyond the 'explicit claims of the participant' (Smith et al. 2009:88), I commented on the potential meanings of these claims. Smith et al. (2009) observe a tendency for those new to IPA to remain at a descriptive rather than interpretative level, adversely affecting the depth of analysis. I found an interrogative approach, as suggested by Smith et al. (2009), particularly helpful in moving the analysis beyond description. This involved commenting on interesting sections of the interviews in a questioning format, highlighting potential meanings and returning to the data as a whole to determine whether there were any emerging answers to those questions. For example, in Faye's first interview, she stated: *'…until I'm allowed to be that deafblind person at work, I can't be that deafblind person'.* Some of the conceptual comments related to this claim took the following form: *Does she need permission to be deafblind and if so who gives this permission? If she can't be that deafblind person, who is she when at work? Being herself at work would render her vulnerable, so she performs as someone else?* Such questions led me to consider such concepts as control and identity.

Biggerstaff and Thompson (2008:9) note that at this level of commenting, the concept of bracketing somewhat 'gives way' to interpretation: here, IPA analysis reflects Heideggerian rather than Husserlian phenomenology (Poletti and Anka 2013), as that interpretation is inescapably informed by the researcher's own experiences and knowledge. In this study, my professional knowledge and experience inevitably influenced the interpretation. As suggested by Smith et al. (2009), I considered the relationship between my existing knowledge and the new understandings emerging from the data, and recorded these reflections; in doing so, while not denying my pre-understandings, I sought to ensure that 'the interpretation was inspired by, and arose from, attending to the participant's words, rather than being imported from outside' (Smith et al. 2009:90) (for examples of annotated participant interview transcripts, see Appendix F).

It was also important to recognise the professional knowledge and experience of the British Sign Language interpreters involved in the interviews, and how this may influence the interpretation. Gathering information on their biographical background and experience was therefore essential, as discussed in the next chapter.

4.3.3 Step Three: Developing Emergent Themes

Having completed the exploratory commenting on a set of participant interviews, I moved to the third stage of analysis: developing emerging themes (Smith et al. 2009). Smith et al. (2009) observe that at this stage, the dataset consists of the transcripts and exploratory comments. Rather than searching for themes across all eight participants as described by Cooper et al. (2012), I focused on one participant at a time, and identified patterns and relationships within the exploratory notes (Smith et al. 2009), enabling me to maintain an idiographic focus. Smith et al. (2009:91) note that this stage of analysis 'represents one manifestation of the hermeneutic circle': having commented on the transcripts as a whole, I began to focus on discrete parts of the interviews, but in a way influenced by the former commenting (Pietkiewicz and Smith 2014). As recommended by Smith et al. (2009), where particularly resonant sections in the transcripts had been highlighted, I engaged in more detailed micro-analysis of such passages. The interpretation emerging from this micro-analysis was checked for consistency against other sections of the transcripts and the interview as a whole.

I recorded identified themes, which were expressed as single words or succinct statements, in the opposite margin of the transcript to that of the exploratory comments (Smith et al. 2009, Pietkiewicz and Smith 2014). Themes principally related to psychological concepts, as is customary in IPA (Biggerstaff and Thompson 2008, Smith et al. 2009), and reflected both the participants' expressions and my interpretation of these (Cooper et al. 2012, Smith et al. 2009) (see examples of transcripts in Appendix G).

4.3.4 Step Four: Searching for Connections Across Emergent Themes

The fourth stage of analysis involved mapping how the themes identified fitted together (Smith et al. 2009). Smith et al. (2009) offer no prescription as to how analysts should do this, but encourage creativity and innovation. Themes from the whole transcript were listed, and I discarded any that had a 'weak evidential base' (Pietkiewicz and Smith 2014:8) and those that were not clearly related to the research questions (Smith et al. 2009, Loo 2012). In order to identify connections between the emerging themes to form 'clusters' (Shinebourne 2011), rather than merely reading and reviewing the typed list, I adopted the more creative and manual approach recommended for novice IPA researchers by Smith et al. (2009): I cut up a hard copy of the typed list of emergent themes, so each was on a separate piece of paper; these where then moved around on a large table, with conceptually similar themes being placed together and opposing themes placed apart (see Appendix H).

Smith and Osborn (2003) suggest using a metaphorical 'magnet' to pull some themes together and push others apart, which proved useful. I kept a written record of my decision making during this process, including decisions to discard themes. I gave each identified cluster a descriptive label (Pietkiewicz and Smith 2014) in order to name super-ordinate themes. As recommended by Smith et al. (2009) I then created a word document file with the title of each super-ordinate theme, and within this listed the contributing emergent themes and relevant sections of the transcripts. In order to 'locate… themes in an ordered system that identifies the main features and concerns identified by the… participant' (Biggerstaff and Thompson 2008:11), I developed tables documenting the structure of themes and super-ordinate themes and the associated transcript page and line references (See Appendix I, Table 13).

4.3.5 Step Five: Moving to the Next Case

Once steps one to four had been completed, I moved on to the next participant's set of interviews and began the analytic process again. Although Biggerstaff and Thompson (2008) suggest using the themes identified in the analysis of the first participant as a means of identifying themes in other participants' interviews, I felt this challenged IPA's idiographic commitment. Smith et al. (2009) acknowledge that the earlier analysis inevitably impacts on future analysis, but contend that the researcher must be open to new themes emerging from each participant's interviews. Researchers must therefore 'bracket the ideas and concepts which emerged from the first case' (Shinebourne 2011:61). Concluding steps one to four for each individual participant before progressing to the next step, rather than completing step four across all participants (a possibility suggested by Smith et al. (2009) in studies with larger numbers of participants) supported my ability to maintain an idiographic focus.

4.3.6 Step Six: Looking for Patterns Across Cases

The final step in IPA analysis requires the researcher to identify patterns across all participants' interviews (Smith et al. 2009). As in earlier steps, I worked with hard copies rather than IT software: the tables developed at step four were placed alongside each other, and I looked across these in order to identify connections and relationships between the themes and super-ordinate themes. To support this process, I responded to the questions posed by Smith et al. (2009:101): 'What connections are there across cases? How does a theme in one case help illuminate a different case? Which themes are the most potent?' I paid attention to the recurrence of themes and super-ordinate themes across all interviews. Smith et al. (2009:107) observe that there is 'no rule for what counts as recurrence'; I considered a theme to be recurrent if present across more than half of the participants (see Appendix K). I also made note of any 'disconfirmatory cases': themes evident in one participant's interviews presenting as 'at odds' with those of all or most of the other participants (Biggerstaff and Thompson 2008). Before confirming these as 'contrasting themes', I revisited the relevant transcript to check for misunderstanding. I kept records of decision making in this process, contributing to the research audit trail.

On the basis of this identification of patterns and connections, I developed the final table of themes across all participants, locating these within super-ordinate themes and including illustrative direct quotations from the transcripts for each participant. During this process, some themes were renamed or reconfigured. The final master table of themes can be found in Appendix J, Table 14.

4.4 Being an 'outsider' researcher

The extent to which qualitative research authentically conveys the experience of participants is indicative of its quality and trustworthiness (Padgett 2008, Berger 2015). Acknowledging that the notion of a 'neutral interviewer' is unrealistic (Enosh et al. 2008:463), reflexivity is important (Carolan 2003, Berger 2015), as it involves exploration of how my positionality in relation to participants influenced both data collection and analysis, and thus the co-construction of knowledge (Johnson and Rowlands 2012, Berger 2015). Particular consideration should be given to whether a researcher shares the experience of the participants: whether the study is undertaken from an insider or outsider perspective (Kanuha 2000, Eppley 2006, Dwyer and Buckle 2009). Dwyer and Buckle (2009) observe that as researchers note the ways in which they differ from their participants, they also recognise similarity. Determining my own position as outsider or insider was therefore complex. I have worked with deafblind people for over a decade, and as a human being, have shared the experience of feeling vulnerable. I also shared religious and political beliefs, and my sex, sexual orientation and ethnic origin were the same as some participants. Nevertheless, I am sighted-hearing and of a different age. Recognising such complexity, some qualitative researchers reject the insider-outsider binary; arguing that they move between positions throughout their research, occupy both or the space between, they call for abandonment of the insider-outsider dichotomy (see, for example, Eppley 2006, Dwyer and Buckle 2009, Obasi 2014, and Berger 2015).

When conducting qualitative research into human experience, Dwyer and Buckle (2009) question whether it is ever possible to be a true outsider. Contrastingly, Obasi (2014:63) contends that undertaking academic research 'automatically places us as outsiders'. To some extent, I occupied both insider and outsider positions in relation to different aspects of the participants' lives. Nonetheless, my shared experiences were less evident than my status as a sighted-hearing researcher studying the experiences of deafblind participants; in the words of Obasi (2014:75), this difference was the 'most discernable in the researcher/researched relationship'. As such, my position was predominantly that of outsider.

Though different positions have both advantages and limitations (Kanuha 2000, Dwyer and Buckle 2009), being an outsider strengthened the study in several ways. Offering a level of objectivity (Eppley 2006), being an outsider rendered probing and 'exposing the obvious' in the interviews (see section 4.2.7) more natural, encouraging participants to elaborate in depth on their experiences. Furthermore, as Berger (2015) notes, participants were less inclined to presume knowledge and offered detailed explanations. This was particularly evident in relation to the nuances of communication methods used. Being an outsider also prevented participants' experiences being inaccurately understood as shared with my own; the risk of 'assumptions of similarity' is evident in insider research, affecting data collection and analysis (Dwyer and Buckle 2009:58). For example, as an insider in her research with lesbian women of colour, Kanuha (2000) describes being distracted from participants' narratives in interviews, as she reflected on similarities in her own life. Finally, as an outsider, the participants were positioned as the experts. Berger (2015) maintains that this is empowering in research with marginalised groups. Because deafblind people, including the participants in this study, can be perceived as incapable or incompetent (see sections 2.7.2.4 and 7.5), this is especially important.

Being an outsider researcher is not without its limitations. It is argued that an outsider can never fully comprehend or convey experiences that are not personally encountered, and that insider researchers are therefore better placed to provide an in-depth understanding and interpretation of participants' lives (Berger 2015, Dwyer et al. 2015). An outsider interpretation remains partial, as some meanings are inevitably overlooked (Obasi 2014). However, as acknowledged in IPA research, knowledge is co-constructed through the interpretative activity of both participants and researcher; as such, the thesis offers *a* credible account of participants' experiences, not the only one (Smith et al. 2009). Being an insider may also facilitate easier recruitment and an increased sense of trust and rapport, such that participants are more willing to share their experiences, increasing the depth of the data gathered (Obasi 2014, Berger 2015). Nevertheless, Pillow (2003) and Dwyer and Buckle (2009) maintain that insider status is no guarantee of a trusting interview encounter, but rather the abilities and genuine interest of the researcher. The techniques I used in establishing rapport and trust are described in section 4.2.7; the provenance of my deep interest in the field is located in personal experience, as described in the introduction to this thesis. Furthermore, being an insider or outsider is not solely determined by the researcher (Richards and Emslie 2000). Throughout the interviews, participants occasionally positioned me as an insider, when they commented that the impact of certain sight and hearing loss conditions, particular equipment, and specialist services would *already* be known to me.

4.5 Conclusion

Informed by the research approach and previous studies with deafblind people, I used in-depth semi-structured interviews as my method of data collection. Learning from my professional experience, the pilot interview and the limited literature on the practicalities of interviewing deafblind people, I used a range of strategies to gather rich data. Nonetheless, I often had to adapt these to ensure their usefulness when interviewing my participants. This included identifying and meeting receptive and expressive communication and language needs, and adapting enabling techniques, such as the use of silence and ways of indicating attentiveness. As interviews were completed, I reviewed the video recordings and transcribed them.

My approach to analysis followed the iterative six-step IPA process described by Smith et al. (2009). The BSL interpreters' contribution was essential to this process and the analytical activity involved work with both the written transcripts and the video recordings. To maintain IPA's idiographic commitment, I completed steps one to four for each participant individually before moving on to the next participant's dataset (step five) and then looking for patterns across ‘cases’ (step six). Writing up the findings as an ‘account of the interplay between the interpretative activity of the researcher and the participant’s account of… experience’ (Eatough and Smith 2006:120) completed the analysis. These written accounts are presented in subsequent chapters.

CHAPTER FIVE - WORKING WITH INTERPRETERS

5.1 Introduction

As noted in Chapter Three, interpretative phenomenological analysis is informed by hermeneutics; the approach recognises the interpretative role of both the participants and the analyst (Biggerstaff and Thompson 2008, Shinebourne 2011). It is essential that the analyst engage in the 'double hermeneutic', interpreting the participants' interpretations of their experiences (Smith et al. 2009), as this adds depth to the analysis and moves it beyond description. Nevertheless, in research involving participants who do not share the same language as the researcher, such as this study, language interpreters and language translation may also be involved. Indeed, the increasing number of such studies (Temple 2002) has resulted in interpretation and translation becoming 'everyday practices in social research' (Young and Temple 2014:130). Just as interpretation of data is informed by researchers' experience and knowledge (Biggerstaff and Thompson 2008), it is important to recognise that the knowledge and experience of language interpreters may also influence interpretation of the data. This final methods chapter outlines how and why I decided to use British Sign Language interpreters (both visual and tactile), and in order to enhance study rigour, considers both their identity and role. I then describe my approach to the transcription of the interviews involving British Sign Language interpreters, and outline how I make use of illustrative direct quotations throughout the thesis.

5.2 Interpreting and Translation in Qualitative Research

5.2.1 The Involvement of Interpreters in Qualitative Research: Background

While the involvement of interpreters can have an influence on studies (Temple 2002), exploration of their role and influence was largely absent in the research methods literature up until the early 2000s (Jentsch 1998, Squires 2009). Writing in 2002, Temple observed that the involvement of interpreters often went unacknowledged. Where it was noted, there was little discussion of the practical matters relating to interpretation and translation (Murray and Wynne 2001) nor any exploration of associated methodological concerns (Almalik et al. 2010). Although a body of research using various methods explores interpreting and translation as a discipline in itself (Tipton 2014, Hessman 2018), Almalik et al. (2010) highlight the paucity of published material considering approaches to evaluating interpreter quality and impact on qualitative inquiry in other disciplines. However, although Temple (2002:845) argues that the insights of interpreting and translation studies have been 'hidden from mainstream research', her work on cross-language and cross-cultural studies, and that of others (for example, Birgit Jentsch, Rosalind Edwards and Allison Squires), has increased the visibility of interpreters and translation in qualitative research.

As described in the previous chapter, some writers have commented on practical matters relating to interpreter involvement in research, including the time and resources needed to make the necessary arrangements (see, for example, Jentsch 1998, Regmi et al. 2010). Other researchers have explored the ethical and methodological implications of interpreter-research participant relationships (Berman and Tyyskä 2011, Edwards 2013). Squires (2009) suggests that failure to respond to these methodological matters can adversely affect the trustworthiness and rigour of research. Writing in the context of research with Deaf people who use British Sign Language, Young and Temple (2014:130) argue that the decisions researchers make about interpreting and translation are also 'epistemological ones, because… they mediate what is known, how it is known, and who is seen to tell'.

5.2.2 Deciding to Involve Interpreters: Giving Voice to Hidden Populations

Reflecting concerns that 'degrees of articulateness' have influenced involvement in social research (Coles 2001:503), there are increasing calls for researchers to ensure that voices once unheard are now rendered audible (Murray and Wynne 2001, Padgett 2008, Smith 2008, Borer and Fontana 2012, Poland and Birt 2018). In the context of social work and social care research, Ryan (2014) argues that failure to hear the voices of marginalised groups 'impoverishes' our understanding of social care experiences. Furthermore, failure to facilitate the involvement of such groups results in their voices becoming 'ghettoized in specialist literature' (Harris and Roberts 2003:21). For example, Werngren-Elgström et al. (2006) note the absence of older sign language users in mainstream gerontological research, and Jaiswal et al. (2018), in their scoping review of the global deafblind literature, observe the exclusion of congenitally deafblind participants from some studies, owing to communication challenges.

The inclusion of marginalised groups can thus be considered a strength of social research (Sixsmith et al. 2014); I therefore chose to include older deafblind people using British Sign Language (both visually and tactually) in this study. Where participants and researcher do not share a language, involvement is ordinarily facilitated via interpreters (Almalik et al. 2010, Edwards 2013): Almalik et al. (2010:265) argue that it is interpreter involvement that 'can enable the researcher to hear the seldom heard voices'. As noted in the previous chapter, although I possess British Sign Language qualifications, my skill level is neither native nor near-native fluency; as such, in order to include Celia and Anthony in the study, as British Sign Language users, I decided to involve interpreters. As Jentsch (1998) observes, this choice necessitated further decision-making, relating to, *inter alia,* the skill and qualification level of the interpreters used, their professional status, and whether or not they are known to the participants.

Qualitative researchers must ensure that participants' perspectives are accurately represented (Regmi et al. 2010); they therefore need confidence in the interpreters involved (Murray and Wynne 2001). Nonetheless, there appear to be very few guides to using interpreters in research (Temple 2002) and limited literature on approaches to evaluating interpreter impact on research processes (Almalik et al. 2010). This is particularly apparent in relation to studies with participants using signed languages (Ladd 2003, Arndt 2010b, Young and Temple 2014), notwithstanding the fact that signed languages themselves have been researched using a range of methodologies for over five decades (Hessman 2018); as noted in Chapter Two, in studies with deafblind people, the involvement of interpreters and their impact on the research are rarely explored. Alys Young and Bogusia Temple have offered more detailed examination of interpreting and translation in studies involving signed languages (Temple and Young 2004, Young and Temple 2014). Recognising that interpretation in this context is cross-language, cross-cultural and cross-modality, they highlight the risk of semantic loss

(Temple and Young 2004). In their studies of both visual and tactile signed language, Metzger et al. (2004) identify eight types of interpreter utterance that were not direct translations of the participants' signed language. Particular features of signed languages, such as multi-channel signs, are '[n]otoriously impossible to translate' (Young et al. 2014:65) and individual signs may also have more than one possible translation in English (Evans 2017a), further contributing to the challenge of ensuring accuracy (Russell 2005). Having decided to involve interpreters, it was important that I considered how such matters impacted on my choice of interpreter and their role in the research.

5.2.3 Rendering Interpreters Visible in the Study

Drawing on her review of the nursing and health journals' methods literature on cross-language research, Squires (2009) developed a list of criteria for evaluating the management of interpreters in qualitative research. She argues that paying careful attention to how the identity and role of interpreters are described in the research contributes to increased trustworthiness of the study. The role of the interpreters in data collection and analysis was described in the previous chapter. Here I focus on identity and interpreter credentials.

Although 'interpreting provision in the UK and elsewhere is highly heterogeneous', consisting of trained and untrained individuals (Tipton 2014: 466), Jentsch (1998) and Squires (2009) both recommend the use of professional and qualified interpreters. This recommendation is supported by Almalik et al. (2010), who observed significant differences in the accuracy of interpreting between lay and professional interpreters; they suggest that use of lay interpreters has the potential to affect the quality of data collected and subsequent analysis. I decided to use interpreters registered with the National Register of Communication Professionals working with Deaf and Deafblind People (NRCPD). When working with deafblind people using tactile British Sign Language, the question of qualification is, however, complex. A 'Registered Interpreter for Deafblind People' is ordinarily a professional qualified to interpret using deafblind manual, not tactile British Sign Language (Department for Work and Pensions 2017). Formal qualifications in tactile British Sign Language have only recently been developed by the accrediting body, *Signature* (formerly the Council for the Advancement of Communication with d/Deaf People), and these are not, at the time of writing, available (Signature 2016, Department for Work and Pensions 2017). Indeed, while the qualification has been developed, there are currently no training centres delivering the course, as it has not been possible to source suitable tutors (Signature Trustee 2017, personal communication, 18 December). There are a limited number of studies on tactile signed language (Collins and Petronio 1998, Schwartz 2008, Spooner et al. 2018) resulting in knowledge gaps and consequent calls for further investigation (Rose 2018). Nevertheless, research has identified particular differences between visual signed language and signed language received and expressed through the tactile modality (Collins and Petronio 1998, Mesch 2001, Schwartz 2008, Dammeyer et al. 2015). These differences respond to the necessity of encoding the visual non-manual features of signed language tactually, and are embodied in variations to, *inter alia,* hand-shape, location, morphology, orientation, the marking of questions, and syntax (Smith 1994, Collins and Petronio 1998, Mesch 2001, Schwartz 2008). Owing to such differences, I sought registered and qualified British Sign Language interpreters who had additional experience and skills in tactile communication.

Young and Temple (2014) challenge the notion that professional status and qualification are the priority of research participants however, noting that trust in the interpreter may be more important. As participants from minority populations may be anxious about matters such as confidentiality (Murray and Wynne 2001), it was important that I paid careful attention to participants' preferences, as these may impact on the preparedness of the participant to discuss sensitive topics (Oleson and Jansbøl 2005, Young and Temple 2014). For example, as noted earlier, Anthony did not wish to be interviewed in the presence of an interpreter known to him, and his preference was honoured.

Researchers have also commented on the benefits of using a consistent interpreter throughout the life of a study (Levinger and Ronen 2008, Squires 2009, Almalik et al. 2010) and the need for interpreters to have knowledge of research processes in addition to linguistic skills (Edwards 1998, Jentsch 1998). Nonetheless, Temple and Young (2004) highlight the role that resources and funding availability play in a researcher’s choice of interpreter and the extent of their involvement. In this study, availability of funding was not the only challenge, but also the availability of appropriately skilled professionals. A search of the National Registers of Communication Professionals working with Deaf and Deafblind People in October 2014 (repeated in July 2017) identified only six professionals with the appropriate qualifications and experience, for England and Wales. As a result, arrangements had to be made well in advance, and in the interviews with Celia, it was necessary to work with both a Deaf British Sign Language user with experience of tactile British Sign Language, and a British Sign Language/English interpreter, as described in the preceding chapter.

While consistency of interpreters and their having knowledge of research processes may be recommended, the limited number of suitably qualified and experienced interpreters with whom to work restricts the options available to researchers working with deafblind people. This challenge is not acknowledged in Squires’ (2009) evaluative criteria, perhaps reflecting the fact that only one of the 40 papers reviewed in her work involved signed language, and this was visual not tactile signed language. I was able to maintain consistency of interpreter for each of the participants using tactile British Sign Language, albeit that there was not one consistent interpreter throughout the study as a whole; this necessitated careful and advanced planning. I also sent the interpreters copies of the participant information sheet, research protocol, interview schedule, and consent form, in advance of the interviews. Such an approach is considered useful (Jentsch 1998, Murray and Wynne 2001), as it makes interpreters ‘sensitive to the research topic and aims’ (Edwards 1998:200).

I adopted the strategies described above in an attempt to enhance the quality of the interpreting and to reduce translational error. However, to position interpreting as a merely mechanical process, which can be rendered unproblematic through the use of techniques for technical ‘accuracy’, is to perceive language as a neutral medium and interpreters as objective conveyors of meaning across languages (Temple 2002, Berman and Tyyskä 2011). Such assumptions reflect positivist epistemologies (Squires 2009, Young and Temple 2014). From constructivist/interpretivist epistemological perspectives, interpreters are recognised as active producers of knowledge (Jentsch 1998, Temple and Young 2004, Temple et al. 2006). Edwards (1998:197) argues that 'researchers need to acknowledge that they carry out interviews *with* rather than *through* interpreters'.

I note the active involvement of the interpreter, particularly when the communication is tactile. How can he not be involved? How can he be seen as neutral? He laughs, he confirms understanding, he is touched by [participant] in order to communicate; it is he, not me, who is physically touched by [participant].

Extract from Reflective Diary: 18/07/2016

Interpreters have their own perspectives, experiences, background and culture, which will inform and shape their translation (Temple 2002, Tipton 2014, Spooner et al. 2018); researchers using constructivist/interpretivist epistemologies must therefore render the role and identity of the interpreters visible and critically reflect on their impact on the research process (Almalik et al. 2010, Berman and Tyyskä 2011, Young et al. 2014). Temple (2002) recommends including biographies of interpreters in methodological discussions, covering matters such as social location and specialist skills: these are therefore found in section 5.2.4. The names and details of all three interpreters have been used with their express permission.

5.2.4 Interpreter Profiles

Jay Thomas-Morton (BSL/Tactile BSL Interpreter for Interviews with Celia)

A fully qualified British Sign Language teacher/assessor, Jay has also been a Deaf Relay Interpreter for almost twenty years. He is Deaf and grew up in a hearing family. Two of his family members are also qualified British Sign Language/English interpreters, and he experienced bilingual communication growing up. Jay holds a Higher National Diploma in Digital Media from the University of Wolverhampton, and qualifications in deafblind communication and guiding, counselling, teaching and assessing, and qualifications relating to his interpreting and teaching business. Jay has worked with several deafblind people, mostly in medical and clinical settings, as a Deaf relay interpreter. He has provided deafblind interpreting at conferences, in social settings and for deafblind people attending appointments with various professionals and services. Jay has been company director at 'Communication Plus' for thirteen years, and for the last nine years, has worked at Word of Hands (a British Sign Language Community Church) as a pastoral leader.

Tracie Hunt (BSL/English Interpreter for Interviews with Celia)

Tracie is a Trainee Sign Language Interpreter. She has Deaf parents and identifies as a CODA (Child of Deaf Adults). As a family, Tracie and her parents and siblings attended the local Deaf sports and social club regularly; she was involved in both the Hearing and the Deaf world as she grew up. After leaving school, Tracie worked as a receptionist at the local Institute for The Deaf for four years and completed the National Vocational Qualification (NVQ) Level 3 in British Sign Language. In 2007, Tracie joined an interpreting and training agency, as a communication support worker; through this agency, Tracie completed her Level 6 NVQ Certificate in British Sign Language. At the time of writing, she is now freelance and is completing her Level 6 NVQ Diploma in Sign Language Interpreting.

Tom Mould (Tactile BSL/English Interpreter for Interviews with Anthony)

Tom is a fully qualified British Sign Language/English interpreter. He grew up in a Hearing family with only limited exposure to d/Deaf people and sign language. It was at the age of 18 that he decided to learn British Sign Language. The Level one course peaked his interest and on discovering he could study British Sign Language at University, he transferred onto the BA (Hons) Deaf Studies course at the University of Central Lancashire (UCLAN). Following graduation, Tom enrolled onto the PGDip BSL/English Interpreting and Translation at UCLAN, and has now been qualified for five years. During Tom's time at university he took a particular interest in working with deafblind people. As part of his employment at university he worked with a deafblind tactile British Sign Language user and has since worked with various deafblind people who use tactile British Sign Language, Visual Frame British Sign Language and other communication systems. Tom has co-presented a paper regarding the lack of deafblind inclusive training for interpreters in the U.K. and trained interpreters working with deafblind people at an international conference.

5.2.5 Interpreters, Translation and Transcription

The involvement of interpreting and translation is not limited to data collection and analysis: it is also required in the act of transcription. Moving from the medium of the spoken word to the written word is itself an act of interpretation (Smith et al. 2009, Ellingson 2012, Harding 2013, Young and Temple 2014). Johnson and Rowlands (2012:106) suggest that 'obtaining a verbatim record [of an interview] is the ideal, if the subsequent analysis is to be valid and meaningful'. Nevertheless, the notion of a verbatim written transcript is problematised when transcribing interviews with participants using visual and tactual British Sign Language, as this language does not have a written form (Young and Temple 2014). As Young and Temple (2014) highlight, moving from signed language to written transcript involves both a change in modality and a change in language: it is an act of translation. Managing this translation to produce a written transcript is further complicated when one considers the cultural features of British Sign Language, not easily captured in written English (Ladd 2003), its grammatical features (for example, signs for nouns, which have a 'built-in' adjective or verb) (Sutton-Spence and Woll 2006), and the 'problems in attempting to represent signed utterances in two-dimensional space (on paper) when in reality they occur in four dimensions' (Young and Temple 2014:143).

Hearing and Deaf academics undertaking research with those using signed languages have commented on the difficulties inherent in the production of a written transcript that accurately represents participants' expression and meaning (see, for example, Ladd 2003, and Arndt 2010b). There is no straight-forward 'how-to' guide offering a clear solution (Young and Temple 2014) and researchers must take their own decisions on their approach to transcription, in ways consistent with their epistemological and ethical approach (Harding 2013, Young and Temple 2014). In preparing the transcripts of Celia and Anthony's interviews, I adopted an approach similar to that described by Arndt (2010b): I produced an 'interim' transcript by repeatedly watching the film of the interviews, and playing, pausing and rewinding the video as I wrote each phrase. These interim transcripts were not solely a record of the audible, spoken English words of the interpreter, but drew on careful observation of the participants' signs and my own knowledge of British Sign Language. English idioms or utterances voiced by the interpreters, such as ‘you know’, ‘kinda like’ and ‘erm’, were not transcribed if not linguistically enacted by the participants. Nonetheless, recognising that those using sign language may also combine language and communication methods (Young and Temple 2014), where Celia or Anthony used vocalisation, finger spelling or deafblind manual, this was recorded. The interim transcripts also included queries and tentative corrections of the interpreters’ voiced over translation, recorded in red type font (for example, see Appendix L).

Murray and Wynne (2001) recommend working with a second interpreter to review transcriptions for translation accuracy. As the interviews were video recorded, I did not work with a second interpreter: this would have compromised confidentiality. Nevertheless, I met with the original interpreters, and together we reviewed the videos and ‘interim’ transcripts. This was an immensely time-consuming process, but offered the interpreters an opportunity to pay careful attention to conceptual equivalence and nuance of meaning (Berman and Tyyskä 2011, Temple et al. 2006), in addition to responding to queries and correcting translation errors. The ‘interim’ transcripts were subsequently amended.

As noted in the preceding chapter, although initially viewed as an opportunity to review the accuracy of translation, my meetings with the interpreters actually formed the first steps of data analysis, as participants’ meanings were discussed, queried and debated. The involvement of interpreters in this process of reviewing, checking and initial analysis enhances the trustworthiness of the study and credibility of the findings (Squires 2009, Regmi et al. 2010, Berman and Tyyskä 2011, Evans 2017a).

5.2.6 Direct Quotations: Representing Participants and their Language

As noted in Chapter Four, in reporting study findings, IPA research makes use of numerous illustrative direct verbatim quotations (Griffin and May 2012). I had to consider carefully how Celia and Anthony’s direct quotations were to be reported, as the presentation of research findings in a language different to that of data collection may pose a challenge to the validity of research (Almalik et al. 2010). However, this was not just a methodological matter. Temple and Young (2004) argue that the way researchers represent both participants and their language is also a political matter. British Sign Language is central to Deaf identity and culture (Kyle and Woll 1988), yet its very existence has been challenged throughout its history: the reasons for this are described in the Deaf studies literature. Although the UK government recognised British Sign Language as an official language in its own right in March 2003, it continues to lack full legal status (British Deaf Association 2014). Temple and Young (2004) maintain that attempts at erasing British Sign Language have been directly associated with the oppression of culturally Deaf people. Uncritical presentation of quotations from Celia and Anthony in English, could therefore 'reinforce the political invisibility of the language and its users' (Temple and Young 2004:166), an outcome not congruent with my professional value base.

Inclusion of video clips from the interviews would have compromised confidentiality and participant anonymity; I therefore had to consider an alternative approach. The option of including quotations or words in the source language (Temple et al. 2006) was not available, as British Sign Language has no written form. Young and Hunt (2011) suggest including both a translation and transliteration: direct quotations are presented using atypical grammar. Deaf academic Paddy Ladd has made use of this approach, presenting direct quotations from British Sign Language using participants in atypical English grammatical forms, alongside contextual information (Ladd 2003). Other researchers in the field have used glossing: a gloss is a written representation of the meaning of a sign using an English word, ordinarily written in capital letters (Sutton-Spence and Woll 2006). For example:

English Translation: When my mother died, I was thirty-three.
Sign: MOTHER MY DEAD THIRTY-THREE ME

Although these approaches avoid rendering the source language invisible (Young and Hunt 2011), they fail to reflect its linguistic complexity (Young and Temple 2014). Furthermore, Temple et al. (2006) point to evidence that such approaches reinforce stereotypes and present non-English users as 'illiterate others'. Young and Temple (2014:149) contend that this is particularly problematic in relation to Deaf participants, as a result of 'persisting stereotypes of Deaf implying dumb, in the sense of stupid'.

Chapter Two identified that deafblind people also report feeling vulnerable to being seen as incompetent or stupid. These approaches were therefore rejected in favour of that adopted by Ellis and Hodges (2013a), in their study involving people with Usher Syndrome: following a direct quotation, the symbol '(I)' is added, indicating that the words represent an English translation of signed language. Where appropriate, I built upon this approach, by incorporating linguistic observations, as illustrated in this example taken from the transcript of Celia's first interview:

Celia: *I want to be in my own home, my own, I've heard from [friend]* **(I)** [Adds multi-channel sign used to mean 'No way, not for me']

First Interview with Celia (27.16-7).

5.3 Conclusion

The interpretation of qualitative data is informed by researchers' experiences and knowledge; this chapter acknowledges that as I had decided to involve sign language interpreters in the study, their knowledge and experience would also influence interpretation of the data. My decision to use interpreters was informed by a desire to 'give voice' to those who have been neglected in mainstream gerontological literature. Nevertheless, inclusion of interpreters and translation in qualitative inquiry, especially IPA research, raises methodological matters which unless addressed impact on the trustworthiness and rigour of the study.

There are few guides to using interpreters in research and limited literature on approaches to evaluating interpreter impact on research processes, particularly in relation to studies with sign language using participants. Drawing on Squires' (2009) criteria for evaluating the management of interpreters in qualitative research, I sought to address matters such as interpreter skill, qualification, consistency and participant preference. However, Squires' criteria fails to acknowledge the limited number of suitably qualified and experienced interpreters for deafblind people in the UK with whom to work, which restricted some of the options available to me. Furthermore, although matters relating to skill, qualification and consistency were addressed, to position interpreting as a merely mechanical process would have been to perceive language as a neutral medium and interpreters as objective conveyors of meaning; this was not congruent with my epistemological perspective. In both this and the previous chapter, I render the interpreters' identification and role visible. To ensure the visibility of British Sign Language itself, in subsequent chapters, as both an ethical and political statement, I explained in this chapter how I built upon the approach to direct quotations used by Ellis and Hodges (2013); this approach also serves to safeguard more authentic representation of the participants' voices and experiences. The participants are introduced in the next chapter.

CHAPTER SIX - THE PARTICIPANTS AND THE RESEARCHER

6.1 The Participants and The Researcher: Profiles

The eight participants are introduced here; pseudonyms are used to maintain anonymity. I also include a brief account of my own background in order to outline my positionality in relation to the study.

6.1.1 Mike

Mike is a white British man, in his late fifties, who lives in supported accommodation; this consists of his own flat and communal areas to meet with other tenants. Care and support is available on site, during the day, and Mike accesses this. Mike is deafblind as a result of Usher Syndrome (Type II). He has been deaf since birth, experiencing a severe bilateral hearing loss. He has had sight difficulties because of retinitis pigmentosa since his teens but experienced significant sight loss at 24 years of age. He now has total sight loss. Mike communicates expressively with speech, but can also use deafblind manual when interacting with deafblind friends who use this method. Receptively, Mike communicates using his residual hearing, supported by two behind-the-ear hearing aids and he occasionally makes use of deafblind manual. For permanent information, he uses Grade One Braille. In addition to deafblindness, Mike has experienced some mental health difficulties. Mike has previously worked at a college on a voluntary basis, teaching students about deafblindness, but no longer does so.

6.1.2 Celia

Celia is white British woman, in her early eighties, who lives with her daughter. She is deafblind as a result of Usher Syndrome (Type I). She has been profoundly deaf since birth, and identifies as culturally Deaf. In her early teens, Celia developed sight loss because of retinitis pigmentosa, which has progressed throughout her life; she now has a very small field of vision. Aged 70 she also developed cataracts in both eyes. Celia communicates expressively using British Sign Language and receptively using tactile (hands-on) British Sign Language and deafblind manual. In good light, Celia can access standard print and information on an iPad. Celia has been in paid work during her life, but has been retired for some years. In addition to receiving support from her family, Celia makes use of direct payments to fund communicator-guide support.

6.1.3 Faye

Faye is a white British woman, in her early fifties, who lives with her husband. She is deafblind because of Usher Syndrome (Type II). Faye has experienced deafness since birth and began experiencing sight loss in her teens. Retinitis pigmentosa was formally diagnosed when Faye was 30. She communicates expressively using speech, and receptively using residual hearing supported by two behind-the-ear hearing aids. Faye can access print in good light. She is currently in paid employment. Faye has had contact with both local authority social services (sensory loss team) and specialist charitable organisations, but currently has no ongoing formal care and support.

6.1.4 Matthew

Matthew is a white British man, in his late forties, who lives alone in his owner-occupied house. He is deafblind because of congenital rubella syndrome (CRS), and has therefore been deafblind since birth. His sight was affected further, when 20 years ago he sustained injuries in a car accident and lost his left eye. Matthew communicates expressively using speech and receptively using residual hearing supported by two behind-the-ear hearing aids. He accesses printed material through speech reading computer software and computer magnification. Matthew is supported with a range of tasks by his parents and does not currently receive formal support from the local authority. He has had some contact with specialist charitable organisations.

6.1.5 Phillip

Phillip is a white British man, in his late fifties, who lives with his wife in a ground floor flat. He is deafblind because of Usher Syndrome (Type III) and describes being deafblind for well over half of his life. Phillip experienced hearing loss in early adulthood and began using hearing aids in his late 20s. He is now registered severely sight impaired (blind), having experienced progressive sight loss during his adulthood because of retinitis pigmentosa. His formal diagnosis of Usher was made approximately seven years ago. Phillip communicates expressively using speech and receptively using residual hearing, supported by two behind-the-ear hearing aids. He accesses permanent information using audio material. In addition to deafblindness, Phillip has experienced mental health difficulties. Phillip has been in paid employment, but retired early on health grounds. He currently receives local authority commissioned communicator-guide support.

6.1.6 Anthony

Anthony is a white British man, in his early seventies, who lives in sheltered accommodation. He is deafblind as a result of Usher Syndrome (Type I). He has been profoundly deaf since birth, and identifies as culturally Deaf. Anthony began to experience sight loss in childhood because of retinitis pigmentosa; this became more significant in his early 20s and by 48 years of age he had total sight loss. Anthony communicates expressively using British Sign Language, with occasional inclusion of signs from American Sign Language (ASL). Receptively, he uses tactile (hands-on) British Sign Language and deafblind manual. He is also familiar with block alphabet and will use this with those who are not skilled in tactile British Sign Language or deafblind manual. Anthony accesses permanent information using braille and a braille display attached to his computer. He has worked with people throughout his adult life, in both paid and unpaid welfare and support roles. Anthony uses direct payments from the local authority to fund communicator-guide support.

6.1.7 Rose

Rose is a white British woman, in her early seventies, who lives alone in her owner-occupied house. She is deafblind because of congenital rubella syndrome (CRS) and has been deafblind since birth. Rose communicates expressively using speech and receptively using residual hearing, supported by two behind-the-ear hearing aids. She did not use hearing aids until she was 30. Rose is aware of and can use deafblind manual and British Sign Language fingerspelling. At the current time, she does not use these methods of communication herself. Rose can access large print when viewed in closed proximity; she also makes use of magnification software on a computer to access emails. In addition to deafblindness, Rose experiences some physical health difficulties. Rose has enjoyed a professional career, but is now retired. She is involved in a number of local social and support groups, and attends her local church. She is known to the local authority social services (sensory loss team) but currently has no ongoing formal care and support service.

6.1.8 Caroline

Caroline is a white British woman, in her late sixties, who lives with her husband in their owner-occupied home. She is deafblind because of Usher Syndrome (Type II). Caroline experienced deafness from birth and began wearing hearing aids aged six. Her sight difficulties began in her early teens, and retinitis pigmentosa was formally diagnosed when she was 25. Her sight loss progressed and she was registered severely sight impaired (blind) when she was 43. Caroline communicates expressively using speech, and receptively making use of both her residual hearing supported by two behind the ear hearing aids and lip-reading. Although Caroline has a very restricted field of vision, her visual acuity is such that she can access standard print. Caroline has had professional paid employment in a range of roles, but is now retired. However, she continues to engage in some voluntary work. She has contact with specialist charitable organisations, principally as a volunteer. She does not use local authority funded nor privately funded ongoing care and support services.

6.1.9 Peter Simcock: Researcher

I am a white British man, in my early forties, and live with my husband in our owner-occupied home. I am sighted-hearing, but have deaf, Deaf and deafblind family members. The deafblind family member acquired dual sensory loss in later life. Following the completion of a law degree, I undertook voluntary work for one year, which included volunteering in a deafblind club. I subsequently completed a Masters degree and professional qualification in social work, and worked as a specialist social worker for deafblind people for two local authorities in England. I left practice in 2010 and commenced a career in social work education. I am currently a senior lecturer in social work at a university in the Midlands and teach predominantly on social work law and core skills for practice modules. I am a member of Deafblind International, and in 2019 became the Chair of its acquired deafblindness network (AdbN).

CHAPTER SEVEN - FINDINGS: EXPERIENCING VULNERABILITY

7.1 Introduction

Nine superordinate themes were identified following analysis. These are listed in Table 14, Appendix J. As shown in Table 15, Appendix K seven of these themes apply in all eight cases, while two apply in seven. This first findings chapter explores how participants make sense of their experiences of vulnerability, considering the first two research questions posed: what does being vulnerable mean to those ageing with deafblindness? What do those ageing with deafblindness feel vulnerable to? Three superordinate themes were identified: felt vulnerability as multi-layered: about, to and when; vulnerability as dependent on the response of others: misunderstanding; and vulnerability as dependent on the response others: perceptions of incapability. The first theme shows how participants experience their vulnerability as layered, describing not only what they feel vulnerable about and what they feel vulnerable to, but also the times, settings and situations when they feel or have felt vulnerable. These layers are not invariably discrete but are often interwoven, with instances of one impacting on another. The second and third themes describe how the participants' experiences of vulnerability are often consequent on or exacerbated by two types of response from others: misunderstanding and the perception of incapability. Participants describe being and expecting to be misunderstood and/or perceived as incapable, and detail experiences of when they have felt vulnerable in such situations. Being misunderstood or perceived as incapable impacts on the feelings and behaviours of the participants. The findings are presented as a narrative account and use extracts from the interview transcripts to provide evidence for each theme (Smith et al. 2009). Where words contained in the interpretative accounts of the data are in italics, these are also the direct words of the participants.

7.2 Felt Vulnerability as Multi-Layered: About, To and When

The complexity of defining vulnerability was considered in Chapter One, section 1.4.1. Initially some participants found it difficult to explain the phenomenon or provide examples of their own experiences of it. Mike and Caroline first responded by questioning my own understanding of the concept, while others queried the place it had in their lives:

> *Faye: … it may have been a word that I, erm, kind of shelved, if, you know, not, not used and avoided (5.24).*

> *Rose: And when in fact when I've been trying to think of incidents when I've been going through, thinking of the, there were very few things I could actually think about, err, remember (26.47-27.1).*

When describing their understanding of the term generally, some participants used the language of risk and danger. While certain participants comment on vulnerability as an experience common to all people, it is also associated with inherent characteristics:

> *Rose: Erm, she, he was only vulnerable because, erm, well he had health problems yes, I think he had a heart problem (57.3).*

Nevertheless, when describing their own experiences of vulnerability, participants used the language of emotions of varying intensity. Participants describe being *upset, worried, anxious, scared* or even *overwhelmed* or in state of *panic.* When telling of an employment situation in which he felt vulnerable, Phillip explains how he was *bewildered* and goes on to describe the range of emotions he felt, including confusion and upset. For Matthew, being vulnerable can go beyond emotion and is sometimes experienced physically:

> *I can get very tight and I can go, I can go from decent temperature to a bit cold (12.39).*

> *Took my blood pressure… it went from normal, up there [raises right hand] in the hospital, down there [lowers right hand] when I came home (16.11-15).*

> *I get very worried and I, I sweat (62.6).*

Although their experiences of vulnerability may differ, data indicate that the way in which participants make sense of these is to consider them as layered. In describing their experiences of felt vulnerability, participants tell not only what they feel vulnerable about and vulnerable to, but also about the situations and times *when* they felt vulnerable. As Faye describes:

> *… and the other thing about vulnerability is it sort of takes on, sort of different levels, as well, it's kind of quite a general thing… or it might be sort of like quite specific things… So I think it's sort, like I say, it takes on, sort of several levels as well (6.25-32).*

7.2.1 Feeling vulnerable about

Although not felt constantly, some participants describe a general feeling of vulnerability, associated with worries or concerns about broad matters such as one's job (Faye) or health (Caroline). Participants also feel vulnerable about the future. For Matthew, this is associated with not knowing whether he will experience further deterioration in his sight and hearing. Celia refers to the progressive and non-curative nature of Usher syndrome to assert that her vision will deteriorate. Consequently, she feels particularly vulnerable about the future:

> *I was thinking about the future, about my vision, it's terrifying (I) (4.25).*

It appears that it is not just possible or probable further deterioration in sight or hearing that contributes to worries about the future, but also the challenges such deterioration may bring and how one would address these. As Rose explains:

> *It is quite a daunting thought… to think that if my sight got worse and my hearing got worse, how would I manage (73.8-9).*

Faye's felt vulnerability about catastrophes or disasters is something she describes as developing as she has aged and impacts on her previous enjoyment, though not willingness, to fly. For others, as they have aged it is not new matters they feel vulnerable about, but rather, a general feeling of vulnerability develops as the cumulative outcome of previous experiences. Phillip describes how ongoing mobility difficulties as a result of public transport problems and hazards such as overhanging branches make him *feel extremely vulnerable* but also *all contribute to [his] general feeling of* vulnerability. Although she does not consider it as generating felt vulnerability, Caroline similarly explains how an experience of unrequested help at a train station, involving physical contact she describes as *like an assault,* has resulted, *from that point,* in a general feeling of being at risk of similar events. Childhood experiences also contribute to general feelings of vulnerability much later in life. Rose explains that although an assessment in childhood identified no special educational needs, her elder sister's school would not accept her. Having had this initial rejection, in the following extract, she movingly describes the ongoing impact of being excluded from a school outing, which she interprets as being related to her deafblindness and associated needs:

> *I can remember going to be taken to a pantomime at Christmas. So naturally, erm, I asked mum if I could go, and she said yes, but the school wouldn't take me [pause]… I wasn't given a verbal answer, but I can, err, my interpretation of this is I was too big a liability to them… Erm, but I have never forgotten that [shakes head]. That just [pause] really, really hurt me very badly (3.34-47).*

It is not just participants' own experiences that contribute to general feelings of vulnerability. When explaining their concerns about being a victim of crime, participants refer to news stories on the radio (Phillip) and hearing *terrible tales* (Caroline) about offences against older and disabled people. For Celia, having never been in a care home, it appears that some of her concerns about such places arise from being told of negative experiences by a friend:

> *I know an old friend of mine… She explained to me, she was in an old people's home… Something bad happened. She said she kept £40 in her purse, in her pocket. And the next night it had vanished. And the staff had taken it… I'm telling you, they were bad there, I won't go… if I was to go into an old people's home, then no, no, no [pause] No…. I want to be in my home, my own, I've heard from [my friend] [multi-channel sign then used to mean 'No way' or 'Not for me'] (I) (18.23-27.17).*

7.2.2 Feeling vulnerable to

Participants identify specific outcomes to which they feel vulnerable, illustrating a characteristic of the phenomenon as potentiality rather than actuality. Phillip describes feeling vulnerable to *all sorts of things*. Nevertheless, all the outcomes participants highlight feeling vulnerable to are negative. One set of outcomes described is physical harm and injury. Mike and Matthew explain how they feel vulnerable to cuts and burns when using kitchen utensils and preparing food. Mike goes on to describe how he might eat undercooked food, as a result of being unable to see his meals, leaving him feeling vulnerable to physical ill health:

> *… sometimes in can be very dangerous. If you eat something and you haven't been cooking it properly, and it's got ice in it, it can make you very ill (33.23-25).*

Feeling vulnerable to physical injury as a result of falls is also described (Faye and Rose), and Phillip explains how he has injured himself as a result of bumping into cabinet drawers that have been left open and how overhanging branches scratch his face when walking unaccompanied outdoors. It appears that further deterioration in sight and hearing is also an outcome to which participants feel vulnerable, particularly as changes in vision and hearing are experienced throughout their lives (see Chapter Eight, section 8.4.1). This is not unique to those with acquired progressive conditions, such as Usher syndrome; Rose, who has congenital rubella syndrome, tells of the *fear of losing [her] hearing completely*. Describing the possibility of deteriorating senses and a decline in physical and mental health, Faye describes feeling vulnerable to increased dependency on others, culminating *ultimately* in an ability to *look after yourself.* For Celia, who has support from her daughters, similar experience manifests itself in feeling vulnerable to becoming a burden:

> *I'm only a bit worried about too much of a burden on her [points to daughter], both my daughters (I) (11.30-2).*

Some participants cite feeling vulnerable to being a victim of crime, with brief reference to being unable to hear *intruders* coming into the property (Celia), or being physically attacked or assaulted (Phillip and Matthew). Nevertheless, participants do not tell of experiences of actually being a victim of crime, and this particular concern does not dominate their interviews or appear to preoccupy them. Matthew and Rose do describe feeling vulnerable to being taken advantage of or exploited. For Rose, this negative outcome was realised. She recalls how a lodger living with her went away for a few days. On his return, she felt something was wrong but gave him access to her home. It was not until the actual lodger returned a few days later, that she realised it was his brother, posing as him, who had been staying in her home; he had taken advantage of the impact her deafblindness has on her ability to recognise people. Although she acknowledges that she was not in any danger, the memory of the event *still horrifies [her].* It appears that previous experience informs the outcomes to which Rose feels vulnerable. However, it is not the potential for actual harm, associated with being taken advantage of, that informs this feeling, but rather the way in which it makes Rose *very aware of [her] weakness.*

Feeling vulnerable to isolation or increased isolation as one gets older is identified by some participants as an outcome to which they feel vulnerable. This can go beyond fear of reduced social connections, social interaction and being alone. For example, Anthony and Faye express a fear of being *cut off* and losing contact with the *rest of the world* as they struggle to reach out to others. Isolation is associated with being othered, as well as with social interaction difficulties related to communication and deafblindness:

> *Faye: I worry that people will perceive me as being somebody in a world of their own (19.31-2).*
>
> *Anthony: The narrowing of the communication, the contact with the world, is one of the vulnerabilities… I try and make people comfortable; they think I'm living in a different world (I) (4.46-5.7).*

Similar to the other participants, Caroline discusses negative outcomes such as personal injury, being a victim of crime, and further sensory impairment and difficulties managing this. Nevertheless, unlike other participants, for her, these are outcomes she feels *at risk of* rather than factors engendering felt vulnerability:

> *I do feel at risk sometimes, but not vulnerable (16.17-8).*

It appears that a potential negative outcome in itself does not provoke felt vulnerability; the phenomenon is only experienced by Caroline at specific times, when other elements are present. Some of these elements are shared by other participants, as considered in the next theme.

7.2.3 Feeling vulnerable when: vulnerability as time, setting and situation specific

During the interviews, all participants offered accounts of times *when* they feel or have felt vulnerable. These stories dominate their interpretations of their experiences, rather more than their descriptions of the matters they feel vulnerable about or negative outcomes they feel vulnerable to, such as those outlined above. Although telling of times of worry, fear and panic, participants also describe times of relief, security and safety, emphasising the transitory nature of their felt vulnerability and challenging any notion that it is constant. These times can be fleeting moments, a period of time or even a time yet to come:

> *Faye: I knew I was getting in the way, and I just felt quite vulnerable at that particular moment (7.31).*
>
> *Celia: I didn't feel safe for the last two years. I told my daughter, and she agreed… She came to live with me… I feel comfortable, feel safer, feel better. Spot on! [multi-channel sign] (I) (2.25-30).*
>
> *Rose: Mostly when I'm out. I don't think, I don't sit and, erm, ponder over it at home, but I do, it does occur to me when I'm out (15.34-44).*
>
> *Caroline: I don't feel that [pause] that's what vulnerable would mean to me…*
> *Me: Hmm hmm. Do you ever feel vulnerable?*

> *Caroline: [pause] Not yet.*
> *Me: Not yet.*
> *Caroline: Not yet, but it could come… I don't at the moment feel vulnerable (15.34-16.18).*

Participants' accounts also reveal the situational and setting specific nature of their felt vulnerability. It is apparent that the experience is not centred on being deafblind, but rather consequent on the situations and settings participants find themselves in. Actions such as crossing roads (Celia and Matthew) and opening the door to unknown callers (Celia and Rose), specific settings such as hospitals (Anthony and Matthew) and being outdoors (Matthew and Rose), the reactions and responses of the people one encounters (Anthony and Phillip), and even the weather conditions (Mike and Rose) may all contribute to felt vulnerability. While the settings and situations are unique to each participant, data indicate shared elements of the vulnerability felt: social settings; losing control or being controlled; the inability to withstand; lacking the full picture; and unavailable or ineffective support. These shared elements are considered next.

7.2.3.1 Social settings

Mike describes enjoying an active social life, regularly attending a local Deaf club and socialising with the supported accommodation staff at his home. With a sense of unhappiness, others tell of a reducing social life, as they get older, and express a desire for increased social interaction in response to fears of social isolation (see section 7.2.2). Nonetheless, it appears that social settings engender feelings of vulnerability for many participants. Engaging in conversation with others can be rendered hard work because of the impact of deafblindness on receptive communication, and anxieties arise in relation to mishearing conversation, responding inappropriately and consequently appearing foolish. Yet it not just communication difficulties that impact adversely on the experiences of participants in social settings. Matthew explains how sight loss related difficulties identifying people he knows to converse with result in him *standing on [his] own half the time*. Similarly, in the following extract, Rose explains how problems initiating and engaging in conversations with others result in her exclusion from social interaction:

> *… say for instance after a church service… when there are people milling around, and it, I find it very difficult to, erm, join a, join a group that are already talking…Erm, which might sound silly but the, but the reason being that I can't interact because I don't get eye*

> *contact… you're excluded until you can make contact and if I, if for instance I was talking to someone, and then somebody else wants to talk to that person, they just come, come up, they im-, immediately engage with that person and you're just left standing (31.43-32.11).*

As a result of increased visual impairment, Celia and Anthony now receive British Sign Language tactually. LeJeune (2010) observes that in this way, for culturally Deaf people, sight loss poses unique communication challenges. Celia and Anthony describe a sense of isolation within Deaf community social settings, associated with such challenges. Celia describes having to withdraw from conversation with other Deaf people at the Deaf club, because of her need for one-to-one communication. Not only does this impact on her interaction with Deaf community members at the Deaf club, but also appears to result in reduced communication outside this setting. In this way, previous enjoyment of social interaction with Deaf peers, is replaced with anger and frustration:

> *At Deaf club, the people there, they're all signing, I'm looking around, it's impossible… now I can't see them… before, all signing, it was lovely… I was fuming inside; I'd come home and get upset… So I'd go back, one, two, three, four times now, so I've given up. No one 'phones me, no one texts me, no one FaceTimes me, no one [bangs hands on table] (I) (25.22-43).*

It is not only the need for one to one communication that produces challenges within such a setting, but also other Deaf people's abilities and willingness to use tactile British Sign Language and the subsequent reduced quality of the interaction. Mirroring Matthew and Rose's experiences, Anthony explains how such matters contribute to his being left alone in a social setting:

> *… a Deaf person of mine might tap me on the shoulder and say hello to my name and spell my name… but then they go off to someone else, and I'm left on my own… And I feel like saying, 'No, come and sit down, sit with me', and they don't, they don't want to… I understand Deaf people want to be able to just sign and communicate, and using tactile sign language can be difficult… I understand why, but the isolation comes from that breakdown (I) (8.4-15).*

Some participants engage in social activities with other deafblind people, either in person or online. Such interaction is described as offering shared understanding and a sense of belonging. In the context of difficulties maintaining connection with the Deaf community as observed above, Celia expresses with joy a sense of being accepted when interacting with *people the same as me* on an online forum for people with Usher syndrome. Nevertheless, the heterogeneous nature of the deafblind population and associated plethora of languages and communication methods used by deafblind people, contributes to a situation in which social interaction is not necessarily easier but is actually more problematic, as Caroline explains:

> *...some of the people who come along are profoundly deaf, and they do struggle to lip-read... and if you have to keep on repeating what you're saying, it's very much like the situation I find myself in with a hearing person... They're repeating and they must get fed up... I quite need speech to be clear in order for me to understand. So I can communicate better with hearing people... than I can with deaf people (11.47-12.17).*

Such interaction with other deafblind people is also described as offering no guarantee of social relationships or friendship:

> *Caroline: ... there isn't anybody that I can interact with, other than with other deafblind groups... But just as with anybody else, the fact that somebody's sharing a hearing and sight impairment doesn't mean you're going to become bosom buddies (7.29-32).*

7.2.3.2 Losing control or being controlled

Participants describe feeling vulnerable when they sense they are not in control or are being controlled by others. It appears that being unaware of what is happening or where one is going (Phillip and Celia), not knowing what to do (Anthony and Faye), and being told what to do or controlled by others (Mike, Anthony, Celia and Caroline) can all result in a discernable sense of lost control. Faye recalls being persuaded to go on a night hike with friends, at a point in her life when her vision had begun to deteriorate. Her sense of vulnerability develops as her deafblindness combined with being in an unfamiliar environment with very little lighting put her *most out of my elements*.

Anthony's interpretation of vulnerability as being *about control [or] somebody controlling* is illustrated by his lack of felt vulnerability when travelling alone using taxis, because he maintains control by knowing what to do:

> *I can travel by taxi on my own though, so I think it's about information. Vulnerability means somebody doesn't know what to do, whereas I know what to do... [A] deafblind person is vulnerable... you say 'Go out on your own', and they say, 'How? How?'... Whereas if you tell me that I need to go out on my own, I'll say, 'OK, please phone a taxi, take me there, and how much? This is what I'm doing, I make arrangements... I'm not vulnerable... Vulnerability implies that you're lost and don't know what to do (I) (31.14-24).*

It does appear that maintaining control negates any felt vulnerability (see Chapter Nine, section 9.2.6). Caroline describes a feared future self, in which her physical health, hearing and vision, and cognitive abilities have all declined, such that the potential *net effect* is her being *less in control of what was happening to [her] and what [she] wanted to* *happen to [her].* Currently having an awareness of what is happening around her, because of some residual vision and cognitive capacity, enables Caroline to confidently assert that she does not *at the moment feel vulnerable* and does not consider herself to be *vulnerable to any kind of… abuse.*

Some participants maintain control through the establishment of a routine. It is the disruption of this routine that precipitates a sense of lost control and concomitant feeling of vulnerability or ontological insecurity. For example, Celia recollects feeling *overwhelmed* when the bus she frequently took to visit her daughter was diverted and she became lost *en route*. The disruption to Matthew's routine by others' making requests on his time appears to provoke considerable stress and anxiety:

> *Matthew: Erm [pause] sometimes [pause] you can, you can go quite happy through the day and then someone rights up and says, 'Oh, we want you at X, Y and Z tonight'. What? Bloody hell I can't do that [louder and higher pitched voice]. And they say, 'Yes, you're doing it' [pause]… I get very worried… Bloody hell. I ring my dad, 'Dad, I've got a problem'… Oh, beeeeep [pause]. No, there's, it's, it's, that worries me a lot… I don't like, there's, I don't like getting out of a routine… I've got a routine…*
> *Me: What is it you're worried about?*
> *Matthew: What am I gonna do? [in a higher toned voice]… Well, it's obvious isn't it. What am I gonna do? How am I gonna work this out? (61.49-62.1).*

The requested change in routine appears to reduce Matthew's sense of control, leading him to question his ability to respond. Feeling one's ability to respond or withstand challenge is threatened is an element of felt vulnerability shared by other participants and is considered next.

7.2.3.3 The inability to withstand

Data reveal that it is not necessarily the challenges participants face, but rather whether or not they feel able to withstand them, that generates feelings of vulnerability. Tangible factors such as the physical presence of support or family (Mike and Celia) and intangible factors such as one's own cognitive ability (Caroline) or prayer (Rose), enable participants to feel safe, even in settings and situations otherwise described as engendering vulnerability. Although he describes isolation as the *biggest difficulty* and *highest level of vulnerability*, it appears that it is an inability to cope with isolation, rather than isolation itself, that leads Anthony to experience vulnerability:

> *Isolation first, vulnerability second. I can cope with my isolation... whereas vulnerability, hmm [pause]. If vulnerability came before isolation, then you would be, it implies weakness and helplessness... With isolation I help myself, I pull myself up (I) (30.44-31.4).*

Matthew states that *some people can overcome* better than others, and for him, it is not his deafblindness that impacts on his ability to withstand, but rather that he is not *a very strong character when it comes to holding my own.* Phillip, however, describes how the mobility difficulties associated with his deafblindness directly impacted on his ability to remove himself from a situation in a café in which he felt uncomfortable:

> *I can't get, I can't pick the plate up on my own and move to another table. I can't see, I'm blind... I wanted to. If I could see, I would pick up the plate, the plate up, gone the other side of the room, taken it outside (51.18-24).*

Faye remembers taking a flight to mainland Europe, to visit a friend, and feeling vulnerable as the aeroplane began to bank. She explains how it was not so much the possibility of the aeroplane crashing, but rather her reduced chances of survival, because of an inability to withstand that triggered her felt vulnerability:

> *... if the plane was to crash, then I would be least likely to survive of the passengers. I know this is just a bizarre idea, but it does stay with me... with your kind of dual disability, you're not going to be able to see how to get out, you're not going to be able to hear the instructions... Gosh, you know, if I was in that situation, how would I fare? (23.9-21).*

Getting older was also important in relation to the way participants felt about their ability to withstand. Celia describes being less able to assert herself, as she gets older. Rose similarly describes feeling better able to withstand *the knocks you get* when she was younger. Having previously accommodated several lodgers in her home, she no longer wishes to do so, because she would be *too vulnerable* as a result of feeling *less able to cope with it now.* Having fallen a number of times as a result of unseen obstacles, Faye explains that as she ages, her fear of falling has increased because as an older person, she would not *fall over so easily.*

It appears that factors beyond their own ability also impact on participants' capacity to withstand life's challenges, including having limited resources, such as a reduced network of family or friends and little or no formal support. Fearing retirement from work, Faye describes how paid employment offers her various resources that enable her to withstand certain situations and circumstances: social interaction, financial independence and an environment in which she can demonstrate herself as capable. For Caroline, retirement from paid employment has had a substantial impact, including diminishing her ability to withstand challenges. Comparable to Faye, work provided Caroline with multiple benefits, including social support, a sense of value, worth, status and belonging, and the opportunity to demonstrate herself as capable and competent. Having *given up all of that* she describes vulnerabilities associated with isolation, a limited sense of value and negative perceptions of others in relation to her capability (see section 7.4). Furthermore, in the following extracts, Caroline explains how her particular circumstances earlier in life prevented her from building, or render ineffective, any reserves to withstand such challenges now she is older:

> *When you give up work, and you stop that, there's nothing, unless you've got a ready built circle of friends, and I've not been able to do that... either because I was working, or because I was dealing with children... And it was enough, so I didn't see the need to make friends, and it was too hard to make them, because they couldn't cope with my hearing plus my sight impairment... So it's harder now being retired, because 'A' I've moved away from the area that I lived for 30 years... and I don't know anybody in this area. The sight issues have kicked in more now, they're more noticeable because brand new area that I live in, I don't know the lay out, it was hard to orientate myself. And it's the isolation also comes along with that (6.38-7.10).*
>
> *I still regret giving up work when I did. And I regret moving up to [county]... I think I should have stayed in [previous home city]... I had 30 years of memories there... I knew people... an inbuilt memory of where things are, where the pavement drops, where, what the layout is (25.38-26.4).*

7.2.3.4 Lacking the full picture

Participants experience vulnerability when they lack what Anthony describes as *the full picture*. Anthony explains that this is partly the result of narrowed communication and limited access to information, phenomena commonly associated with deafblindness (see Chapter One, section 1.2.1); and partly consequent on others' failure to provide information explicitly, including that which hearing-sighted people may acquire implicitly during their childhood. As an example of the latter, Rose understands her difficulties in socialising to be in part a result of being unaware of certain non-verbal communication:

> *...nobody ever actually told me the importan-, the value or importance of eye contact... I almost feel a bit let down because nobody did make me aware of it (51.12-19).*

In the context of health worries, Anthony describes how pain or discomfort may provide half the picture, but being unable to see the colour of his urine, for example, means he lacks the full picture, which would help him determine the nature of any concerns.

Contrastingly, participants describe how having access to the full picture diminishes feelings of vulnerability and fosters feelings of safety and security. Having the full picture appears to enable participants feel in control or to promote their ability to withstand, and therefore these elements of experience seem interrelated. Anthony explains how felt vulnerability when travelling alone arises because he does not *get full information.* He adds that when his guide communicates necessary information to him prior to any journey, such as timetables, he is able to travel on trains alone and it helps to *keep me safe.* Despite describing hospital visits as situations when he feels vulnerable, Matthew reports the mitigating effect of having the full picture when attending scheduled appointments:

> *I don't mind that, as long as I know what I'm gettin' into first, then that's fine, yeah (20.40).*

The impact of having the full picture about one's diagnosis and prognosis is not, however, the same for each participant with progressive sight loss as a result of Usher syndrome. Anthony recalls that, as a child, his parents did not explain anything to him about his sight loss, despite having some awareness of it. In this context, using the metaphor of an unfolding secret, Anthony explains how getting a diagnosis in his early forties enabled him to accept his visual impairment, albeit it difficult to do so. Nevertheless, for Faye, while receiving a diagnosis of Usher syndrome was positive in that it gave *a name to it* and reassured her that her sight loss was not imagined, in the following extract she explains the freedom of not knowing:

> *I'm glad I didn't know, err sooner about my sight loss… I think it probably would have stopped me doing quite a lot of things, so… erm, in some ways for me, anyway, it was probably better that I didn't know (51.44-52.4).*

Once she had the full picture, Faye began to question what she was doing and made significant changes in her life:

> *…once it was diagnosed it kind of changed things a bit… it did make you sort of think, 'Oooh, may be I shouldn't be doing certain things', and one of the things I did is, erm, I changed my job so that I was nearer home, so I'd have err easier travel arrangements… I've stopped doing certain things (5.46-6.13).*

Participants do describe feeling vulnerable when they lack the full picture in relation to their immediate environment. For those with residual hearing, it is not unexpected sounds in themselves that generate anxiety, but rather being unable to identify their cause or location owing to sight loss:

> *Mike: When, when fireworks go off or a loud bang behind me, it makes me frightened… when somebody slams the car door or somebody slams the flat door, it frightens me… Because I can't see where it's coming from (7.14-24).*

Being unaware of the presence of others, either outdoors or indoors, similarly provokes anxiety and fear for Celia:

> *I'm frightened in case someone approaches me from behind, I can't hear them. I don't know that they're there, I have to look around… When I'm reading and my daughter comes and taps me, I jump… anxiety (I) (7.5-9).*

The experience of vulnerability when in unknown places was a theme for all participants. This includes being lost or in a completely unknown environment (Phillip and Celia), being in unknown venues, even those associated with socialising and leisure (Rose, Anthony and Faye), being with unknown people (Rose and Faye), and visiting environments that have been altered having previously been known (Matthew). Even one's own home, a place associated with safety and security, can produce feelings of vulnerability, if not known. Caroline describes as *horrendous* the first day in her new home and how lacking the full picture of her environment left her with a *sense of panic:*

> *… the day we moved here it was quite horrendous, because I didn't know, I couldn't find anything. I couldn't find the light switches, and this is a very dark house. Err, I didn't know where anything was and it was just a sense of panic… the furniture's not in a place that I can, I know where it is, that I can, can work round (50.8-15).*

A clear contrast is drawn between being in places known and unknown, in relation to felt vulnerability. As Anthony explains:

> *If I go to a strange place, that I don't know, I'm vulnerable. I can go to places where I know, maybe I could go for a walk somewhere I know, but I'm definitely more vulnerable when I go to places unknown (I) (21.41).*

Illustrating the interrelated nature of the elements that contribute to felt vulnerability, data indicate that although the familiarity of known places results in felt safety, it is being in control in known places, especially one's home, that also prevents felt vulnerability:

> *Celia: I want to get up in my time, when I'm ready, and do what I want to do... When I'm here [home], I can please myself, I can do what I want to do (I) (19.2-5).*
>
> *Matthew: ... if I'm indoors and in my house, fine... you've got your own space, and you can do things the way you wanna do things (12.9-21).*
>
> *Caroline: It is safe, and also erm, it's you, you've tailored it to your own needs (50.7).*

7.2.3.5 Unavailable or ineffective support

Irrespective of their use or not of formal support, participants describe needing help with various activities, including mobilising safely outdoors or in unknown environments, interpreting spoken communication, going out socially, attending medical appointments, and certain domestic tasks. Some interpret the need for such support as dependence:

> *Rose: ...lady... took hold of my hand and walked me through the pub, which was of course in semi-darkness anyway... I couldn't have managed without it (17.8).*
>
> *Anthony: ...if I want to go out, I can't go out on my own, I just can't, I depend on a guide (6.3-4).*
>
> *Mike: I go with a member of staff, everywhere I go, I go with a member of staff (22.35).*

Although some participants identify increased dependence as something they feel vulnerable to, as they get older (see section 7.2.2), data reveal that it is not being dependent itself that generates felt vulnerability, but rather being in situations when the support upon which one is dependent is unavailable. Matthew, Rose and Anthony tell of situations in which their requests for support have been unmet; for Rose, the unavailability of assistance is the *daunting part.* As someone using both formal and informal support, Celia describes feeling vulnerable when alone. Furthermore, it appears felt vulnerability can be especially acute, when ordinarily available and effective support upon which one depends is withdrawn. Using the language of shock and abandonment, in the following extract, Faye recalls an experience when her husband left her alone temporarily in a theatre. Having left Faye to retrieve his dropped car keys, she describes how the *crutch had been taken away*:

> *I didn't really know quite what to do and I, I suppose erm, he's normally so good, you know, he does look after me... he'll take me by the arm if need be, erm, warn me of steps and, you know, lead me, erm. But just in that moment he abandoned me, erm, and I suppose it was quite a shock really that he'd just done that. Erm, so it was sort of like the crutch had been taken away at that moment... I'm used to having him there to, to help me, and just in that*

> *moment it had gone… it was a lot of people around me, I couldn't see them, erm, I couldn't see their faces. Erm, I would have, you know, not been able to understand what they were saying (21.26-39).*

It is not just the absence of human support upon which one depends that can engender feelings of vulnerability. For example, Mike describes how the termination of a paid role educating students about deafblindness prompted feelings of vulnerability, and Faye and Phillip comment on the impact of fading or absent white or yellow paint used to mark out steps. The withdrawal of mainstream facilities can also have an adverse impact on someone deafblind, as Phillip explains:

> *[organisation] have taken away the temporary bus stops, and now, they say, and they now say, an announcement comes on the bus saying, 'The next bus stop is closed' now, instead of having temporary bus stop there, near the, near the bus stop… I still have to get off with a white stick, so I know where I am, you go to the next bus stop. That's no good to me, and lots of other people, we don't know where we are… That's one way of being, of feeling vulnerable (10.41-11.6).*

When support is available, participants' feelings of vulnerability do not emerge, are diminished, or are replaced with felt safety and security. While the presence of necessary human support is important, available mainstream facilities can provide such security. For example, Rose describes how the availability of road crossings in her hometown gives her *a feeling of safety.* Celia recalls an experience at hospital following eye surgery, which had resulted in a period of complete sight loss. Experiencing total deafblindness for the first time, she angrily describes a situation in which she was unaware of what was happening to her and feeling nursing staff removing bandages. The change in her feelings as a result of effective support becoming available, in the form of a nurse with required communication skills, is evident:

> *I was in bed, tucked in, and then someone came up to me, 'what's going on?' [signed to self]… I couldn't see anything. I had a bandage and they pulled that up. It was too bright, can't take it in. I felt angry and wanted to hit them… A few minutes later, another nurse approached me… she picked up my hand, and she signed 'hello' [hello signed in deafblind manual] and I felt relieved, better. She went. I felt better by that (I) (1.40-8).*

It is notable in the above extract that Celia's more positive feelings remain even when the nurse leaves. This appears to reflect the overlapping nature of the features associated with participant experiences of vulnerability: the nurse has provided contact, offering Celia a fuller picture, thus enabling her to better withstand the situation she is in. Similarly, despite Celia feeling vulnerable when alone, knowledge that support will become available seems sufficient to diminish these feelings; Celia has the full picture and maintains a sense of control, enabling her to withstand being alone:

> *When my daughter goes to work… I know I'm alone, but I know she will come and be there… If I was alone [pause] I'd get into a temper. I wouldn't be able to find things. I'd get angry… When she [daughter] wants to go out, she always says, 'I'm going to be back in two or three hours, or she gives me the time. So I know to look at the clock, and I know I'm going to be OK. I know I'm going to be OK because my daughter will be here soon. That's good… I can control myself (I)(32.13-33.2).*

In recounting their experiences of situations in which required support is unavailable, participants further develop their reflections and try to make sense of the reasons for such absence. They describe the non-provision of public funding for formal support or the funding of insufficient hours (Matthew and Anthony); lack of skill among support staff and difficulties finding staff with the appropriate skills (Matthew and Anthony); restrictions to support owing to the decisions of gatekeepers (Phillip); their own reluctance to ask for support (Rose and Faye); professional staff determining certain support provision as beyond their role (Anthony); and misrecognition or misunderstanding of their needs (see section 7.4). A particular experience for Celia and Anthony, as users of British Sign Language for expressive communication, is the misunderstanding of their requests for support. As illustrated in an experience described by Anthony, the non-availability of 24-hour interpreter support combined with misunderstanding by non-signers, results in his request for support being unmet:

> *A similar thing happened to me, one time in an emergency. I'm put in a hospital bed, and I was asleep, and I wake up and I need to go to the toilet. The problem is I don't know where the toilet is. So I press the call button and the nurse comes and I ask, 'Will you please take me to the toilet?' but the nurse didn't understand what I say, and she yanked up my [unclear] and then she left… It's difficult. If I'm in pain, how do you communicate with the nurses, they don't understand (I) (42.25-45).*

While data indicate that for most participants available support diminishes or removes felt vulnerability, Caroline describes a diametrically opposed experience: engagement with support is when she *actually start[s] to become more vulnerable.* Using an image of being taken over, Caroline describes fears of overprotection, related to professionals thinking *they know what's best* and a sense of lost independence. Nevertheless, this is not the only factor in the felt vulnerability she associates with her use of support. Engagement with specialist services and organisations heightens awareness of her own dual sensory loss, which has an *insidious* effect on her self-perception: she begins to question her own abilities and sees herself as someone *who needs to be looked after and protected.* In the following extract, Caroline illustrates this experience, by explaining how mobilising with a communicator-guide generates rather than negates her felt vulnerability:

> *If I'm walking with erm a friend who is [specialist organisation] trained now, err, who used to be a communicator-guide. So I hold her arm, now this is not something I'd ever done before. So you're lose, losing a bit of independence, and you're walking along, and you can actually see the pavement, because my central vision is clear, if I'm looking straight ahead I can see pretty well. So she'll say, 'Watch that bush there', or 'Mind this car's, erm, wing mirror sticking out', and you think, you have to bite your tongue, because you really want to say, 'I don't need you to do that, just, you know, stop thinking about my needs all the time, and that's actually making me feel vulnerable (34.40-9).*

7.2.4 Vulnerability layers as interrelated

It would be inaccurate to suggest that in making sense of their experiences of vulnerability as layered, participants understand these layers – vulnerable about, vulnerable to, and vulnerable when - as discrete. It appears that they are overlapping and interrelated. For example, Matthew and Anthony both describe feeling vulnerable when isolated and feeling vulnerable to isolation. Isolation is a feared negative outcome, but one also feels vulnerable when isolated, not only because of a stated need for human contact, but because it frustrates the ability to develop strategies to withstand other potential negative outcomes, such as depression or loneliness. As Anthony explains:

> *...when I think about my isolation, I've no way of thinking of new things. We're talking about trying to find different ideas. Isolation is something that can prevent me thinking of new things, so when it comes to me not wanting to be depressed, it's always important for me to meet new people, and new people give me new ideas... all these new things, all these different developments, they keep me going, they keep me energised, and keep me from always feeling alone, so I'm not lonely, but I am alone (I) (19.13-30).*

Similarly, just as participants explain feeling vulnerable in situations when they experience a sense of losing control or being controlled (see section 7.2.3.2), such loss of control is a negative outcome participants describe feeling vulnerable to. This relationship between the 'vulnerable when' and 'vulnerable to' layers of experience is also apparent in participants' discussions about unavailable support. For Matthew, the youngest participant, the role of his parents is important here. The transitory nature of felt vulnerability is evident as he asserts *as long as I've got my parents, I'm fine*. Nevertheless, as his parents are ageing, he is acutely aware of a forthcoming time when they will no longer be able to provide the support they currently do because of their own health status or because they have died; this is central in his felt vulnerability to support being unavailable in the future:

> *I get a bit worried about it from time to time… Because they are my parents and they do a lot for me… because of the way the system works in this part of the world… Cos you can't, cos you, cos, erm, you can't say, 'Oh I'd like a personal guide next week. No thank you, you can't have one (89.49-90.13).*

Times, situations and settings when participants felt vulnerable can also influence the negative outcomes to which they feel vulnerable and a sense of vulnerability if finding themselves in a similar situation. Data indicate that this can be case even in situations where participants were not at risk of any actual harm. For example, Celia explains feeling vulnerable when answering the door, following an incident when a stranger came to her home, and she could not identify him on the CCTV owing to his position outside. Such was her felt vulnerability, she declined to open the door. Some time later she learns that the stranger was actually her grandson paying a visit. Phillip rationalises his decision to no longer travel alone to a group he is involved in, by referring to an incident some years ago when he felt particularly vulnerable, albeit that he was not at actual risk nor came to any harm as he feared:

> *I had an incident 20, 30 years ago when my eyesight started to go bad, cos I was trying to get to [location] and I was walking round the back streets, and I actually got lost… And it was frightening…And somebody grabbed my arms, 'Can I help you?' and started walking me… I didn't know where I was going. I have no idea. I felt extremely vulnerable… I said, 'Can you take me to the station please?' Didn't say anything… Ah, fuck knows where he was gonna do, where I was gonna end up. And I was shivering, shaking, everything. Thank God, on that occasion it, he actually took me to the station [pause]. Not to some stairwell or somewhere (48.37-14).*

Felt vulnerability in particular settings appears to have influence even in the absence of actual risk of harm. As Caroline reflects on her concerns about rendering herself vulnerable when outside with her white cane, a visible symbol of her impairment, she acknowledges that in her experience people are *more likely to be helpful, rather than antagonistic* leaving her to ponder if it's *all in my head.*

Participants' responses to different layers of vulnerability can also interact, such that one felt vulnerability is diminished while another is exacerbated. Attempts to reduce felt vulnerability, by avoiding situations when such feelings occur, serves to increase the potentiality of the negative outcomes to which participants feel vulnerable. Rose illustrates this interaction as she describes conflicting views on using a white symbol cane outdoors:

> *On the one hand, erm, it does give me sense of security, but on the other hand, erm, I feel, well do I really need it... And also I am, I am also aware of the fact that it does draw attention to me. On the other hand, that can be an advantage... but not always (36.43–37.6).*

Avoidance of situations when they feel vulnerable can also adversely affect participants' opportunities. Faye recalls declining the offer to attend a course that would have resulted in promotion at work, because of her felt vulnerability in unknown situations with unknown people. She goes on to express with regret a feeling that she has *missed out* by *taking an easier path.* The almost iatrogenic nature of the interplay between vulnerability layers is best illustrated in Caroline's interviews. She describes feeling vulnerable to isolation and loneliness, and a strong desire for greater levels of engagement with people. Nonetheless, her felt vulnerability when in social situations, associated with the risk of appearing stupid, is prevailing. She therefore eschews such situations, even though they offer what she desires, by either avoiding them completely or by presenting as unsociable:

> *I would quite like to talk to them, or talk to somebody on a bus. But I can't take the risk... The risk is, I think, of somebody talking back to me and not, either I misunderstand completely or I don't answer, and they'll either think I'm stupid or they'll think I'm very snooty. Which, neither of those is true. So better not to engage in conversation and let them think that you're... snooty. Erm, I think the overriding thing is you don't want to appear stupid (7.27-28/29.30-5).*

Using metaphor, Caroline goes on to explain how she puts a *kind of shell* around herself for protection in such situations. Retreating into the shell, she can withdraw from social settings or present as unsociable to avoid interaction. Her choice of voluntary work, offering computer based advice and information, enables her to remain protected by the shell, but similarly exacerbates her isolation and loneliness:

> *...being at home all the time, you're communicating a lot by computer, and that's bit soulless... I feel I'm doing something for somebody, which is good for me. But it's lonely in the sense that I don't, it, it's easy not to go out... and to stay indoors, in a safe, familiar surrounding (15.2-13).*

In her second interview, Caroline visualises the shell as *pale blue* and *made of sugar*. It seems to offer her immediate sweetness, in providing protection from being seen as stupid, but is essentially bad for her, as it maintains her isolation and loneliness.

7.3 Vulnerability as Dependent on the Responses of Others

The next two superordinate themes both show the role that the responses or actions of others can have in the participants' experiences of vulnerability. It is evident in the interviews that participants interpret some responses as threatening, intimidating or in other ways hostile or unhelpful. As explained earlier, others' requests can disrupt a much valued routine, resulting in stress and anxiety, and their lack of skill, failure to adapt, or unwillingness to use alternative communication methods can contribute to the participants' reduced social interaction. It appears that others' responses can also impact on the availability or effectiveness of support, the effectiveness of aids and equipment (see section 7.4.3), and lessen the efficacy of the participants' own coping strategies. For example, prior to his admission to hospital, Anthony acquires cards explaining the deafblind manual communication method, to share with nursing staff. His preparations to ensure communication are frustrated however, when the nurses forget to pass these on to other staff at the end of their shift.

The way participants interpret how others might perceive them is also important. In section 7.2.4, it was observed how Caroline's concerns about being seen as stupid were prevailing. The oft overriding nature of how one will be seen is notable in the meanings participants' ascribe to their felt vulnerability, even when there are other objectively identifiable risks. Rose describes never going outdoors without her hearing aids. The main concern for her, is not risk associated with safe mobilising, traffic or warning sounds, but an almost fear of someone engaging in conversation with her while out, mishearing what they are saying, and consequently appearing stupid. Two particular responses that most or all participants feel both vulnerable to and that provoke felt vulnerability when experienced, are feeling or being misunderstood and perceiving others as seeing them as incapable. These are considered next.

7.4 Vulnerability as Dependent on the Responses on Others: Misunderstanding

Michael Gerwat, himself deafblind, argues that the condition 'is the great unseen and unrecognised disability' (cited in Alley and Keeler 2009:3). Participants describe feeling vulnerable to being misunderstood and share their experiences of feeling, being or expecting to be misunderstood. In response to these experiences, participants expand on their discussions, to try and make sense of the reasons for such misunderstanding. Irrespective of these reasons, participants associate a range of outcomes with misunderstanding: changes in their own feelings and behaviour, and a negative impact on the way they understand themselves to be perceived by others, and on their experiences of support.

7.4.1 Feeling, being and expecting to be misunderstood

Participants recollect experiences early in their lives, which they now interpret as misunderstanding. As his vision begins to deteriorate, Anthony recalls how his father understood this as him being *clumsy,* and Caroline remembers *jokes in the family* about her needing to eat *more carrots.* When meeting with the Head Teacher of a potential school, Rose explains that her father denied the presence of any hearing loss and that the dual nature of her impairment was unrecognised by her family for some time. Data indicate that the experience of misunderstanding is significant and ongoing in the participants' lives: it is the first thing Caroline identifies as something she feels at risk of, and participants describe recurring experiences, which they interpret as misunderstanding by family members, the Deaf community, health and social care professionals, and strangers. Phillip and Caroline describe experiences where they have felt staff at specialist deafblind organisations and other deafblind people have misunderstood their impairment. Reflecting on the recurring nature of these experiences leaves Rose to ponder:

> *Err, and it made me think, well actually [pause] how many people really understood me... I think this is part of the difficulty, I felt misunderstood (52.18-29).*

Some participants describe the extent of the impairment being misunderstood; this is particularly focused on sight loss. In explaining her increased difficulties engaging with the Deaf community, Celia believes that *Deaf people really don't understand how bad I am.* Throughout his two interviews, Phillip is keen to stress that he is severely sight impaired (blind) and not sight impaired (partially sighted), noting that he often feels that people *think I can see more than I can.* The following extracts illustrate how Phillip interprets difficult situations as centred on the misunderstanding of the extent, not presence, of his sight loss; the first at the hearing aid clinic and second at the GP surgery:

> *... he was fiddling around with something, and he left a piece of paper on my left, and erm, and a pen... Then he said, 'Oh, could you sign, could you fill out the form and sight in please? [pause]... But his vision was fine [pause]. And I said, 'What? Sorry? Erm, you know. 'What form and what paper?' [pause]. And then I had to wave my stick, 'Look!'... And everyone went quiet in the room [pause]. 'Actually I'm severely sight impaired, not, not, not partially sighted'. 'Oh, sorry, sorry, sorry' (28.6-25).*
>
> *The receptionist at the GP... had always saw me coming in, and looked at me with a stick and everything and thought, yes, he's probably very partially sighted. But actually, I'm not. It's more like severely sight impaired, almost blind (26.4-7).*

Feeling that the impact or nature of the impairment is misunderstood is also described. Recalling her school and college days, Rose tells of fellow students not realising what her *limitations are.* Faye similarly remembers university friends misunderstanding her difficulties seeing in the dark, telling her that she simply *needs new glasses*. For Phillip, misunderstanding of the impact is evident within the processes he must complete in order to access welfare benefits and public services. He questions the need for repeated assessments for incapacity benefits by the Department for Work and Pensions, suggesting that the incurable and progressive nature of Usher syndrome is not recognised. Comparably, in the following extract, he critiques the local authority care and support survey he had to complete, noting how a perceived misunderstanding of the impact of deafblindness renders it difficult for his needs to be accurately captured:

> *On a recent survey I had to fill in, there's a, do you need help indoors? The was [name of local authority] care and support... Question mark, exclamation mark. Question mark, exclamation mark. I'm fine indoors in my own home thank you. But what about some, another home, place, in the borough. It could be, erm, shops, it could be town hall, anything, I need help, all the time (15.4-12).*

Misunderstanding of language, communication and communication based needs can lead to the experience of what Anthony calls *breakdown*. As noted in section 7.2.3.5, Anthony describes how the misunderstanding of his expressive communication results in requests for support being unmet. Celia similarly explains how misunderstandings relating to both her expressive and receptive language and communication method frustrated her attempts to ask for assistance when she was lost:

> *I couldn't make people understand what I was saying nor them replying (I) (15.42-3).*

Caroline recalls a moment of *terror* when her doctor's misunderstanding of her communication needs leaves her feeling unable to cope:

> *... the doctor said something, and I said, 'Oh, Im sorry, I'm deaf'. So he stopped speaking and just mouthed everything. He just started doing lip-speaking. And I just looked, I just looked at him in terror, and I said, 'I can't cope if you don't give me some words, some sound'. And he looked a bit surprised (10.33-41).*

It is not just communication that participants perceive as being misunderstood, but their actions or behaviour. Having a desire for physical contact and needing tactile receptive communication, Anthony expresses concerns about people misinterpreting such contact as sexual in nature; this is mirrored in concerns about his own potential misinterpretation of the touch of others. Phillip recalls having to send information on Usher syndrome to a colleague, after falling into her and being *accused of hitting her.* During the time when she was left alone in the theatre (see section 7.2.3.5), although she refers to feeling vulnerable to getting lost and falling, others questioning her behaviour as she *flounders* is important in Faye's interpretation of the experience, which culminates in marking her out as unlike everyone else*:*

> *I'm trying to put myself in their shoes, trying to imagine them looking back at me seeing this person floundering and not really understanding why I was doing that... at the time I was more worried about, you know, whether I was gonna fall over and how I was gonna get out of the situation... and I, I wasn't really [pause] thinking [pause] well [pause]... I was thinking about what, what, what's this person doing, why is she not moving with the rest, why is she not, you know, like everybody else, and moving along, why is she behaving awkwardly (8.17-31).*

In seeking to lessen misunderstanding, some participants use visual symbols of deafblindness, either explicitly (for example, red and white symbol canes) or indirectly (for example, through their use of listening devices), and some tell others of their impairment directly (see Chapter Nine, section 9.2.1). Nevertheless, it appears that participants perceive that such actions are not always effective, as they describe, with disbelief and frustration, an ongoing sense that their deafblindness is unrecognised or misunderstood:

> *Rose: But you'd be amazed at how many people still don't seem to know or understand what a white stick is for… I remember once going, err, this is, is the sort of situation I find quite frustrating, you go up to the ticket barrier to ask for, for the next train to wherever, and I remember doing this in [city]… and he said, 'Go and look at the board', and I said, 'I've got a white stick [mimes holding the symbol cane forward]… I can't see the board'*
> *Me: Yeah. And how do you feel in those situations?*
> *Rose: I'd like to give them the stick [laughs] (37.15-33).*

> *Phillip: I walk in there with my brother, with a red and white stick… it's very noisy, she talks quite softly. I get out my personal listener [mimes putting this on], attach everything up, headphones, my machine, microphone, everything… And right at the very end, after a long interview, she said, 'Well, could you look at the monitor and just check what I've, what I've written please?' And that made me fuming… I lifted up my red and white stick [lifts up red and white stick which he has with him] and went like this [waves stick in the air, banging the ceiling]. [Shouts] Woooahhh, woooahhh! I can't see the monitor, let alone what's on it!' (30.12-28).*

In the following extract, Caroline shares exchanges with her sister and a colleague, illustrating how even when directly told of the impairment, misunderstanding appears somewhat persistent:

> *…we were having lunch and I was talking to her about erm about this [deafblindness], and she said, 'But you're not deafblind', I said, 'Well according to the Department of Health I am'. It, and I explained what it was about, the communication, mobility. She said, 'But you can communicate', and I said, 'Yes, but look just how much difficulty I had…' and she said, 'Oh, I suppose so'… Somebody, a colleague, saw me once carrying a white cane. She said, 'What's that?' I said, 'Oh, it's because err I've got hearing and sight impairment'. She said, 'But you can see' (24.9-20).*

7.4.2 Explaining misunderstanding

As participants share their experiences, they seek to understand why they and their impairment are so misunderstood. Caroline, Matthew, Phillip and Rose all refer to situations in which they associate the misunderstanding of others with stupidity or ignorance. Nonetheless, this is usually in the context of particular encounters: behaviours seen as rudeness or mockery (for example, a stranger asking Caroline, mobilising with a long cane, why she is taking her *curtain pole for a walk*); in situations where participants have to come harm (for example, people bumping into Matthew when he is out walking with his long cane); or when the other person is young or inexperienced. It appears that unconscious incompetence is also understood to be a contributing factor; Anthony explains that some social workers he encounters often know very little about deafblindness, but *think they know everything [because] they learn at university or college*.

Notwithstanding these negative experiences, difficulties understanding and explaining deafblindness are also acknowledged, leading Caroline, Anthony and Rose all to comment on misunderstanding being no-one's *fault.* Some participants describe their own misunderstanding of the impairment (Caroline, Celia, Anthony and Faye), their diagnosis (Anthony and Caroline) or the purpose of equipment (Matthew). For those participants with Usher syndrome, difficulties in their own understanding of deafblindness occur within the context of late recognition or formal diagnosis of the condition; for example, Anthony was not formally diagnosed until in his 40s, and Phillip in his 50s. As Faye explains, one's own misunderstanding develops a sense of empathy for others:

> *I didn't understand… until I had to learn about my condition, so I know that there is a lot of ignorance, I was ignorant before… even I find it a bit weird… so I kind of appreciate that other people are not really going to find it easy to understand (40.19-35).*

The prevalence of the deafblindness, the terminology to describe it, and its nature are also important. As a minority impairment, it may be outside the experience of health and social care staff. For example, while an inpatient in a mainstream mental health hospital, Phillip describes misunderstanding by the psychiatrist, nurses and other health care staff, but recalls the psychiatrist commenting that they have *never seen anyone like you before come in, somebody with sight and hearing loss.* Complexities in definition and the proliferation of terms for deafblindness were explored in Chapter One. For Caroline, this complexity contributes to her experience of being misunderstood, resulting in her use of terms such as *dual sensory impaired* or *sensorily challenged,* and ultimately, a preference to avoid *describing it at all* to others:

> *But deafblindness… I think it doesn't convey accurately what my sight and hearing is like… somebody thinks, 'But you can see'… somebody starts putting their face very close to you or shouting very loud. And it isn't accurate from that other person's perception… if I can get away with not describing it at all, then I will (28.2-38).*

Faye similarly seeks to avoid describing her impairment, or finds herself telling others of only the hearing impairment, believing deafblindness is *too much for some people to take on board.* Nevertheless, it appears that a felt need to tell others of their impairment is in part related to the invisibility of the condition; this is a further factor participants identify as contributing to it being misunderstood or unrecognised. In Caroline's words, other people cannot *see there is any problem*. For Phillip, the *hidden* nature of deafblindness, which he experiences as *double disability,* is associated with a lack of discernable physical difference in his eyes. However, Caroline and Celia describe situations in which their sight loss has been rendered visible to others, by the use of mobility aids, while their deafness remains hidden. Consequently, Celia explains how she can be perceived as a blind rather than deafblind person:

> *People know that others are blind. They talk to them. They have their canes. Deafblind, you have canes. Deafblind it looks the same. When you're outside, walking, you look fine. They don't know that I'm disabled, they're not aware of it (I) (27.34-7).*

Additionally, some participants interpret the heterogeneous nature of deafblindness to have a role in their experiences of being misunderstood. As perceived by Caroline, people do not always *understand that deafblindness comes in many forms and shapes.* Focusing on the extent of impairment, Phillip describes how another man with Usher syndrome assumed he has a similar level of sight loss, resulting in Phillip needing to explain that he has *actually got worse eyesight than him.* Moreover, homogenising the deafblind population can exacerbate communication challenges. Anthony recalls a period in hospital when he was described by healthcare staff as simply a 'deafblind patient'; no further information was provided to other staff about his actual language and communication needs, as if the term 'deafblind' was sufficient to capture his situation and needs. Stressing that *you can't always compare [deafblind people] generally*, Anthony critiques the training provided by specialist organisations for presenting all deafblind people as requiring assistance in a certain way:

> *And then a guide had had training from [specialist organisation], and he had a different way… and I said 'What's that?', and I said, 'No'… And they were quite resistive and wanted to follow the ways of [specialist organisation] and the training…[B]ut the training was different. [Specialist organisation] tell them you must say… I said, 'No, I like to do it differently' (I) (23.38-24.5).*

Anthony goes on to explain how the homogenisation of deafblind people in training results in a form of misunderstanding that leaves him feeling vulnerable to lost individuality:

> *I think part of it is because they're trained. They learn from somebody who has trained them how to care, and people aren't always treated like individuals… you lose your individuality (I) (59.21-4).*

7.4.3 Outcomes of misunderstanding

Irrespective of the reasons participants ascribe to their experience of being misunderstood, they also describe a range of outcomes resulting from it, which further contribute to their felt vulnerability. Data show that one set of outcomes can be categorised as an impact on the self. Expecting misunderstanding, Faye and Rose sometimes feel reluctant to tell others of their deafblindness and associated needs: despite needing help in an unknown social venue, Rose explains that she was *a bit worried* to ask a person for assistance *in case she wouldn't have, didn't quite understand.* The expectation of misunderstanding is also significant in informing participants' decision-making about the use of equipment, and even the presentation of themselves. For example, for Faye and Caroline, the decision not to use a white symbol cane or mark an existing long cane with red bands, is explicitly associated with such expectation:

> *Faye: that's why I can't use my white stick. Cos I can't use my white stick and then go into work… because people won't understand that (40.17-9).*
>
> *Caroline: I don't put red bands on my white cane, because… I decided that putting red bands on a white cane, either people don't know what it means, or if they do know what it means, they, they won't come and help me, because they think I won't be able to hear or see anything, so there's no point (18.33-7).*

In a poignant point during her first interview, Faye explains that concerns about misunderstanding even prevent her from *being* deafblind at work, suggesting that she is therefore required to present as someone hearing-sighted. It appears that until she is certain that her deafblindness would be understood, she does not have permission to be her true self:

> *…it would be very odd if somebody at work saw me use a white stick, they wouldn't be able to understand how that can be… it is my mindset, I , erm [pause] until I'm allowed to be that deafblind person at work, I can't be that deafblind person, erm [long pause]. They, they would struggle if they saw me with a white stick (8.37-45).*

Rose and Phillip share stories of when they have had a sense that the extent of their deafblindness is disbelieved, as a result of misunderstanding. Rose describes times when others have told her they believed that she *could hear and see more than [she] was letting on* and Phillip interprets a community psychiatric nurse's request for him to go outside and meet his awaiting taxi, as in indication that he *must have thought I could see much more than I could.* Owing to such experiences, and fearing that her condition will be disbelieved, rather than presenting as hearing-sighted, Rose explains how she sometimes presents as more impaired than she is:

> *... if there's somebody here, somebody here in the room with me, and something glittering was on the floor, 'cos of the way of the light shining on it, I bent down picked it up, picked it up, I would feel most vulnerable, because I would immediately think, well they'll think why, why did she see that? She must be able to see better than we think... You might have an understanding of that, but the average person, man on the street as it were, wouldn't know that... And it therefore means, makes it quite difficult sometimes to know, err, would it be, would it better just to ignore that and pretend I didn't see it (81.18-47).*

Misunderstanding and disbelief appear to lead some participants to question the impairment themselves, querying their need for equipment (Rose) or even the condition itself, as the following extract from Caroline's second interview illustrates:

> *So if I say I'm blind, somebody thinks 'But you can see'. And then you think how can, you think yourself, if you really were blind you wouldn't be wasting your time wearing specs would you (28.21-3).*

A second set of outcomes associated with misunderstanding can be categorised as the impact on others. Participants explain how misrecognition or misunderstandings of deafblindness result in situations where they are consequently perceived by others as *rude*, *inconsiderate, unsociable* or, as Faye describes, where people think *I'm ignoring them.* Faye also identifies a sense of anxiety among others, feeling that *they're a bit nervous of me*. Anthony similarly interprets some of others' behaviour towards him as fear, particularly their fear of physical contact and tactile communication.

Misunderstanding is also understood by participants as contributing to the difficulties they encounter in receiving support from others. Participants using tactile sign language assert that people *don't know how to help me* (Celia) or *don't know how to deal with me* (Anthony). Nevertheless, Anthony believes that merely knowing British Sign Language is *not the full answer* and that others need to understand him as an individual.

In the following extract, Anthony goes on to explain how misunderstanding of his needs as a deafblind person, within the mainstream older people's supported accommodation where he lives, results in ineffective support, which he has to alter:

> *There are lots of old people out there, I'm different... So for example, in an emergency, there's the emergency cord [points to emergency pull cord in flat], I put it on the top shelf, and they told me off, and they said, 'No, it has to hang', and I said, 'No, it's my mobility, I follow the wall [indicates with hands feeling around the wall] and I'll end up pulling it. It will be a false alarm, everybody would come to the flat, and nothing wrong'. So I put it on the shelf (I) (33.6-14).*

Although Phillip describes situations in which he feels his needs have been ignored, in part as a consequence of misunderstanding, other participants tell of experiences of unrequested help and overprotection. It appears that these are interpreted as the result of a misunderstanding of, and differing views on, the level of need or risk, as illustrated in the following extracts from Matthew's interviews:

> *I don't have problems getting on and off the buses... but my mother always grabs hold of my arm and says, 'Come on' and tried to make it look worse than what I think it is (24.39-43).*
>
> *Sometimes I get that before I even get asked. 'Come on', swoosh [mimes as if pushing someone along]. I've had that when I'm crossing the road. 'Come on, you wanna cross the road'. 'No', swoosh [mimes as if guiding someone]. Straight across... Geez, that's not good' (57.24-35).*

It is not just the effectiveness of human support that is problematised by misunderstanding. Participants also explain how the effectiveness of aids and equipment is diminished where their meaning is considered to be unknown or misunderstood by others. For example, Rose laments that while walking with her symbol cane can result in others being more considerate, it *doesn't always work* because some people do not *know or understand what a white stick is for*. Similarly, comparing his experiences in France and the UK, Matthew describes a mixed response to his use of a red and white long cane when outdoors:

> *In France, I can go down the street, with my parents, in France [pause] it's like, it's like the sea parting [opens arms wide]. People just go everywhere; they give me a very wide berth. In this country, forget it. Boom, bash [uses arms indicating people bumping into him], they walk all over you. They don't wanna know... Cos they're stupid (71.32-43).*

Such outcomes can be contrasted with the way in which participants describe situations in which they feel that the nature of their impairment was understood and, in the words of Matthew, where people *know how I operate.* In such situations, participants describe feelings of gratitude (Phillip), harmony (Anthony), positivity and relief (Celia). In situations where the impairment is not only understood but also shared by others, Caroline explains how her identity is not reduced to her condition and that she can simply be herself:

> *Yes, I can just be me, just be me, yes… And I'm not defined by my sight and hearing loss, and nobody will think of doing that (61.18-22).*

7.5 Vulnerability as Dependent on the Responses of Others: Perceptions of Incapability

As his final interview came to an end, Anthony exclaimed *deafblind people are not dummies, they're not dummies, they're not stupid.* Feeling vulnerable when and feeling vulnerable to others' perceiving one as incapable is something described by all participants. Such a perception impacts on their experiences, which for some is exacerbated by existing low self-esteem. Within the interviews, participants tell of their pleasure at being recognised as capable, which can support their ability to withstand the challenges they face as individuals ageing with deafblindness.

7.5.1 Feeling, being and expecting to be perceived as incapable

Participants recall childhood experiences, where they feel they were perceived as incapable or incompetent. Describing her earlier life, Rose explains that she knows *for a fact that my father didn't think I was very bright*. She goes on to describe feeling that she was an embarrassment to her father and adds that *nobody ever thought I was any, up to much.* Caroline tells of being bullied at her primary school, an experience involving name calling centred on a perception of her being stupid. This clearly had an impact on her at the time, but also remains with her today, as indicated by her memory of the bullies' names:

> *… a couple of the boys cottoned on to the fact that I was deaf and wore hearing aids, and they took great pleasure, for a couple of weeks, in chanting, whenever I walked in, to the beginning of the school day, they would say, 'Deaf, dumb and damn stupid', quite loudly. I can still remember their names. And I was absolutely terrified that this would become erm*

> *standard practice…. And from being quite an outgoing child, I became much more withdrawn (55.6-27).*

Participants also recollect others having low expectations of them. Both Faye and Caroline describe their parents suggesting that perhaps, unlike their siblings, university was not for them. Caroline goes on to explain how a careers advisor discouraged her from pursuing her interest in a career in teaching, *because of the hearing loss.* Anthony similarly remembers a lack of recognition of his abilities in childhood, despite doing well at school:

> *I did very very well in school and many times, I was first in the class… My mum never, she never said, 'well done'. I was Deaf, so she cried (I) (2.28-31).*

Anthony goes on to have a private English tutor and to learn sign language at school, which he describes as *opening his mind* and developing his *knowledge of the world.* Using the metaphor of moving between worlds, he struggles as he transitions from the restricted world of life with his parents (incapability), to a new world of education, communication and knowledge (capability).

Data indicate that the experience of being perceived as incapable continues throughout the participants' lives, irrespective of their education, career or experience. They describe people becoming impatient when they fail to respond to visual prompts, such as signs to move forward in post office queues (Celia), and report on situations in which they felt patronised or laughed at (Anthony and Matthew). A regular gymnasium goer, Matthew explains how he feels his ability to use the equipment is questioned, somewhat pejoratively, by other users:

> *Yeah, I get laughed at… I have been known to go in to the gymnasium carrying my red and white stick, and what have you, and I leave it in the locker… there are some people there that look at you and think. 'Oh God, him', and some people just stand and go, 'Uhu [mimics laughter] he can't do all that' (69.27-45).*

A feeling that they have been perceived as incapable is also evident within the context of participants' use of care and support services. For example, Phillip explains that his ability facilitating a group at a day opportunities centre is questioned, because he is himself as service-user and not staff, and Rose describes *being treated… like an adolescent although I was what, 50* when she was an inpatient in hospital. Mike angrily tells of a time he was *shouted at* by a member of staff and described to others as being unable to *handle my money* for simply making a mistake:

> *I go into a shop and I wasn't given the right coin, note to the shopkeeper and [staff member] was telling me off you see, and [he] said, and I, and I said, 'I can do what I like with my money' (25.47-9).*

Experiences described by Anthony reveal how support workers expect him to be incapable, resulting in unrequired, albeit well-intentioned, offers of assistance:

> *Like the manager here… She thinks she's helping. No, I can do it by myself. She's amazed, 'You can do it?' Then she goes back to the old people, she works with old people, she helps them. I say, 'No, I can do it' (I) (32.39-46).*

Anthony goes on to explain how feeling patronised by support workers from a specialist organisation ultimately prompted his decision to move to direct payments and directly employ his own communicator-guides. Feeling that he was excluded from being in control of his own support, as workers liaised with their supervisors, rather than discussing matters with him directly, engenders his sense of being undermined:

> *You can talk to me openly; you don't have to go via your supervisor, via your manager. And it didn't feel very fair… I don't like people to talk behind my back… We should be talking direct to each other, not going via the supervisor… Many, many support workers… report, report, report to their supervisors… I say, 'Please let me talk to you… Ask me questions? Don't patronise me (I) (55.7-57.36).*

As shown in section 7.2.4, for Caroline the fear of being seen as stupid can override different concerns, and other participants express feeling vulnerable to being perceived as such. Celia, Faye, and Rose all state explicitly that they feel other people may think of them as *stupid.* It appears that this fear has increased as the participants have aged. For example, both Rose and Caroline explain how, now older, they worry that they will be seen as *has-beens* who have little worth. Matthew describes contemporary society as *survival of the fittest:* as someone with impairment, he therefore feels that *as you get older, it gets worse and worse, and other people look at you and think, 'Oh, he's not good is he'.* Such negative perception from one's own family is even feared, as the following extract from Caroline's interview illustrates:

> *As I get older, I can perceive that my children, also getting older, but thirty years younger than me, might well think, 'Oh mum doesn't know what she's talking about'. That bothers me… That would be, that would be a very vulnerable situation (20.19-28).*

Some of the shared elements contributing to situations when participants felt vulnerable, explored in section 7.2.3, are evident in their experiences of vulnerability associated with the perception of incapability: unavailable support, a lack of the full picture, and an inability to withstand. For example, Caroline expresses a desire for help in her role as Chair of a local Hearing and Sight Impaired group. She explains how the absence of such support leaves her feeling *a bit useless.* Anthony describes how lacking the full picture frustrates his problem-solving capabilities, leaving him appearing to others as unable to cope. Caroline, Phillip and Faye all reflect on how paid employment has provided them an opportunity to demonstrate their capability and thus withstand perceptions to the contrary. As such, for Caroline, retirement has a particular significance, resulting not only in the loss of social interaction and a sense of belonging, but also an environment in which she demonstrated a capable self, resulting in *respect, value* and *status*. It appears that Faye's worries concerning lost opportunities to demonstrate capability are central to her felt vulnerability about losing her job:

> *I don't want to lose my sort of financial independence, I, I want to erm, still show that I'm capable of working, that I can [pause] erm [pause], you know, I'm capable of earning my own living (4.23-5).*

As the participants continue to experience the perception of incapability throughout their lives, they describe feeling that they are *dismissed, ignored, pitied, disrespected, second-class* or *less than* others. Celia even begins to question her own capability, querying in the interviews, on more than one occasion, if she has given *the wrong answers* and describing feeling like she *can't do something.* It is touchingly illustrated in the following extract, as she explicitly infantilises herself because of increased needs:

> *We have chips. Sometimes they fall off the plate and I'm embarrassed… I'm unable to see that. And they fall down on my lap, so it is getting worse. It would be best to have a bib. I feel like a baby, I'll need a bib soon (I) (21.21-5).*

For Matthew, distorted perceptions of capability have been experienced through his predominantly negative encounters with other disabled adults. He describes feeling uncomfortable with the *attitudes* of those he has met in disabled groups, whom he finds *obnoxious* and *very arrogant.* Matthew explains that their presentation of themselves as *better than they really are* results in comments from others, which reveal polarised perceptions of his abilities, neither of which he sees as accurate; he is less than others or portrayed as brilliant:

> *And, and the people say, 'Oh, you do brilliantly well' and I say, 'Yeah, I do alright'. I don't go and, I don't go and flannel it like other people, like other disabled people do, which for me is not nice. I don't, I don't like it (53.30-2).*

The perception of incapability can have an impact on more than how participants feel. Anthony refers to an airline company's rule refusing him permission to fly unaccompanied, which he describes as leaving him vulnerable to discrimination. It is apparent, however, that he interprets the policy to have been informed by the assumption that deafblind people are incapable:

> *That's just the airline rules, it's safety, deafblind and disabled people can't fly on their own... You have to respect human rights... check with my knowledge, safety, if I know. Don't misjudge, thinking that deafblind people can't do that, it's a human right. Ask them, do you know about safety, with life jackets. Yes, with communication. OK, great, you need to be given a chance... People shouldn't be dismissive and say, 'deafblind can't, can't, can't... (I) (47.14-48.12).*

7.5.2 Negative self-perception

The way in which participants felt about themselves is also important in the context of this prominent theme concerning capability. Revealing rather negative views on their own impairment, some participants use the language of being *the problem, incomplete,* having *a bit missing* or there being something that *wasn't right.* Caroline recalls being called to the headmaster's office when a school child and thinking that it was *all my fault* when he became angry because she did not hear his request to 'come in', and Faye describes herself as both *bumbly* and *awkward.*

Notwithstanding their university education and professional lives, Caroline and Rose both downplay their achievements. Rose states that she does not *really shine in anything,* and when reflecting on her father's negative perception of her intelligence, immediately adds, *not that I am very bright.* Caroline describes having a *history of low self-esteem* and sees herself as unimportant. In the following extract, she compares herself unfavourably with other family members:

> *So all my family is high achievers, but I just went to [name of polytechnic], and got my... degree. So I was the low achiever of the family. So I was the thickie... I never, I've never thought that I achieved very much (58.20-59.27).*

7.5.3 Needing and valuing recognition of capability

Having experienced the feeling of or having been perceived as incapable throughout their lives, for some in the context of negative self-perception, participants value and seek out recognition of their capability. Matthew happily states, on more than one occasion, that he often receives a *good report* from the consultant at the hospital. He takes pride telling how the specialist describes him as *the fittest person he sees,* as does Mike when he excitedly describes, in two of his interviews, winning a certificate and trophy for his artwork. Although ultimately deciding against applying for a guide dog, Rose expresses pleasure that she was *given the chance to give it a thought,* despite the associated training and responsibility. For Faye, one of the positives of support from social services' staff is the acknowledgement of her abilities:

> *...they have good advice. Erm, and sometimes they're quite encouraging as well, they're quite erm [pause], I don't know what your experience is, but some sort of say, 'well, good for you being employed', because I think some people do struggle in that area (48.27-30).*

When asked how she would like to be seen, Caroline's first response is *competent* and *capable.* It is when she is able to present as capable that the *shell* she uses to protect herself, as discussed in section 7.2.4, can be removed:

> *... one of the jobs I had was a trainer... And I had no problem standing up in front of err a group of six to eight people and delivering a training course... Interacting with them, talking about the trai- ,the course, the course material. So there, there wasn't a shell in that respect as all, no, because we were all working to the same end, and because I knew my subject. They wanted something from me… the shell does come off (33.34-42).*

Phillip similarly expresses a desire to be seen as capable, urging people to *tell the manager* when they praised his performance in a part time role he fulfilled. The pleasure gained in being seen as capable is apparent in his reflections on the value of such reward over the financial gains from his employment: *it meant ten times more than the money*. Phillip goes on to observe that such recognition is central to supporting his ability to cope, with both his deafblindness and his vulnerability:

> *That's what I freaking, keeps me, keeps me, goes back to the [inaudible] question of how do you manage to cope… And how do you feel about making you less vulnerable and coping with being positive and optimistic, having decent quality of life, and the rest of it for deafblind people (20.4-11).*

7.6 Conclusion

This chapter presented findings related to participants' sense-making of their experiences of vulnerability. Analysis of the interview data identified three superordinate themes. The first of these shows how participants interpret their vulnerability as layered, describing what they feel vulnerable about, what they feel vulnerable to and the settings, situations and times when they felt vulnerable. The latter layer dominated the interviews and data reveal shared elements of the vulnerability experience: social settings, losing control or being controlled, an inability to withstand, lacking the full picture, and unavailable or ineffective support. These layers and elements are not discrete but interrelated and the participants' moving stories demonstrate how vulnerability layers can be combined and how the avoidance of one vulnerability can exacerbate another, in an almost iatrogenic effect.

Data also indicate that the experience of vulnerability can be dependent on the perceptions of others. The second and third superordinate themes focus on this aspect of felt vulnerability, noting a shared experience among participants of misunderstanding and the perception of incapability. Such vulnerabilities can have a negative impact on the experiences of the participants, irrespective of their cause, including negating their own coping strategies or the effectiveness of support.

Within the interviews, participants also describe how getting older is important in their felt vulnerability. This includes descriptions of an increased vulnerability to isolation and the perception of incapability, a felt decline in their ability to withstand challenge and misunderstanding of their needs by mainstream older people's services. Nevertheless, analysis of the participants' interviews identified further meaning in their experience of ageing with deafblindness; these findings are considered next.

CHAPTER EIGHT - FINDINGS: AGEING WITH DEAFBLINDNESS

8.1 Introduction

This second findings chapter explores how participants make sense of their experiences of ageing with deafblindness, considering the third research question posed: what does getting older mean to those ageing with deafblindness? Three superordinate themes were identified: experiencing deafblindness, not being deafblind; new challenges and increasing difficulties; and experiencing change and making adaptations. The first theme shows how participants make sense of their dual impairment, and how this relates to their identity. It describes how the participants' experiences of deafblindness often consist of more than the inability of one sense to compensate for impairment in the other. Challenging any notion that ageing with, rather than into impairment, renders it easier to manage, the second theme describes how participants encounter new and ongoing difficulties as they age. Participants explain how the interaction between their deafblindness and increased age can complicate the effects of both. The third and final theme shows how change and associated necessary adaptation are interpreted by the participants as a key element of their experience of ageing with deafblindness. Like the previous chapter, findings are presented as a narrative account and use extracts from the interview transcripts to provide evidence for each theme (Smith et al. 2009). Where words contained in the interpretative accounts of the data are in italics, these are also the direct words of the participants.

8.2 Experiencing Deafblindness, not being Deafblind

As noted in Chapter One, in England, deafblindness is recognised as a third discrete sensory impairment, in addition to deafness and blindness. Nevertheless, participants predominantly describe and talk about their sight and hearing impairments/ deafness separately. It appears that this has an impact on the way they interpret their own identity, describing themselves in different ways throughout the interviews. In this way, an identity as deafblind is neither stable nor static, and participants seem to have experiences of deafblindness rather than 'be deafblind'. Data indicate that these experiences of deafblindness are multi-faceted and are often created by more than just the difficulties compensating owing to combined sensory loss, described in Chapter One (see section 1.2.1).

8.2.1 Sensory impairments as separate

All participants describe and talk about their sensory impairments separately. At the beginning of their first interviews, Mike and Phillip both introduce themselves as *deaf and blind* and Caroline comments on being *hearing and sight impaired.* When explaining his difficulties, Matthew similarly separates his *sight and hearing*. Anthony makes separation between the two impairments explicit:

> *... because blindness is a different world again, a completely different world from deafness, so I had to struggle with deafness, and then when it comes to blindness... it's a completely different world again (I) (4.12-5).*

Separation of the two impairments is also apparent in participants' descriptions of their fears and their interpretations of the help they require. For example, Rose tells of a *fear of losing my hearing completely* and in describing his required support, Phillip states needing:

> *More of a guide help... And also help with the hearing as well... Things I don't hear properly (7.25-33).*

Developing their sense making, participants reflect on the reasons for such separation. Differing trajectories for each impairment are described, with mixed levels of deterioration experienced, as the participants get older. Caroline believes that there has not *been much change in my hearing,* while her sight loss has gradually deteriorated, albeit that she has some useful residual vision. Conversely, Rose explains that her *right eye is still about the same*, yet her hearing has *gradually got worse.* Data indicate that in some situations and contexts, one impairment is experienced as more significant than the other: in Rose's words, *times when one is more evident than the other.* For example, both Anthony and Caroline comment specifically on the impact of their sight loss when describing their difficulties mobilising, making particular reference to it preventing them from driving a car. In the following extracts, Caroline and Mike illustrate how it is the emotional impact of one impairment that appears more evident than the other:

> *Caroline: ...yes I do think about the hearing and sight. Not the hearing so much, erm, but the sight, yes, it does bother me (21.34-5).*
>
> *Mike: I never used to get frightened, but now I can't see I get frightened (13.13).*

One impairment is not only more evident to oneself at times, but also to others, as Rose explains:

> *... they could see I couldn't see very well, because you can't exactly hide that. But they didn't realise I couldn't hear very well (65.37).*

Some participants focus principally on their sight loss rather than hearing impairment, throughout their interviews. Matthew explains how support from another person acting as *another pair of eyes* facilitates easier social interaction. Even when describing himself as deafblind, for Phillip it is the impact of the sight loss that appears dominant: *as a deafblind person, I can't see.* For Anthony and Celia as culturally Deaf adults, separation of the deafness and sight impairment has particular meaning. While sight loss is experienced only as impairment, being Deaf is of itself interpreted positively. As Deaf children at Deaf schools, they have a shared identity with peers, and describe active and positive social lives. As the following extracts illustrate, it is the emergence of sight loss that is interpreted as problematic, resulting in loneliness and rendering them different to members of their community:

> *Anthony: ... when I was going to go blind, it made me feel quite low... my social life was quite good to that point, I had a lot of Deaf and Hearing friends, quite an active social life. But when I became blind, it was very different, a big difference. The contact I had with my friends got less and less and less... Deaf people offered me a wide world (I) (3.47- 5.9).*
>
> *Celia: I went to Deaf school... I was playing, happy, it was nice, same as everyone... it was fine... Then at the age of nine or ten, I found I'm different from the others... As I got older, as a teenager, 13, 14, 15, I noticed things had changed. I became withdrawn (I) (1.17-23).*

Data indicate that not having a confirmed diagnosis and the timing and order of onset of each impairment are also important. Even though her sight and hearing impairment were concurrent, prior to her diagnosis of Usher syndrome, Caroline separates them, explaining that she *never thought of it as deafblindness*:

> *... still there was no erm correlation made between the sight and the hearing, it was just two separate conditions (5.2-3).*

Caroline was born with hearing impairment, albeit not recognised until she was five years old. Difficulties with her vision started in her mid-teens, becoming more significant in her mid-20s. This timing and order of onset of the impairments also contribute to their separation, impacting on her own experiences and those of family members:

> *I think because they happened at different times in my life, I probably have kept them separate. So the, the deafness came first and then the sight, progressive sight loss started afterwards (27.42-45).*
>
> *… in fact my erm sight loss didn't start manifesting itself until after I'd left home… So this isn't something that my family has got, my other family, my siblings and my parents, ever grew up erm having any involvement with. But the hearing, the hearing aids and that they did (40.9-13).*

Faye, who like Caroline has Usher syndrome Type II, has similar experience. This results not only in the separation of the impairments but influences the way in which she tells others of her condition:

> *… it's sort of like the hearing loss comes first and then the sight loss comes later… it's easier to tell people I've got a deaf problem… that's the first thing I would tell a, a stranger… it's easier to tell people that, than say, 'well actually I've got this sight problem', that seems to come second (31.4-28).*

Nevertheless, now she is older and her sight loss has progressed to the point where it is equally as problematic as her hearing loss, Faye's separation of the impairments has diminished:

> *I suppose now [pause] I, although I don't see them as separate, I see them very much together, erm because they're both a nuisance (31.22-4).*

8.2.2 A mixed and unstable identity

As illustrated in the following extracts, for Mike, descriptions of his own identity and that of others centre on sensory impairment and mode of communication:

> *There's four of us blind and [pause], three can hear and [trails off]… [Person A] had erm, can see, but he can't hear very well. [Person B] who's blind and deaf, can't hear at all. [Person C] is deaf, she can't hear, but she can see. [Person D] is deaf and blind like myself [pause] (2.17-21).*
>
> *[Person E] can hear and he can talk, and he can drive a car. [Person F]… he can't hear and he can't talk, but he can see… And, erm, [Person G] can lip-read and she can see, but she can't drive a car. [Person H] who can see, but not very well, he's got a spot in his eye, and he can lip-read (29.10-16).*

Nonetheless, the way participants describe themselves, in relation to their dual sensory impairment, changes throughout the interviews. It appears that like other disabled people (Peters 2000, Purdam et al. 2008), they have a sense of multiple identities, which impacts on their interpretations of the ageing with deafblindness experience. Some participants describe a former self as a single sensory impaired person, reflecting the cause of their deafblindness and the associated timing of onset of each impairment. When recalling her school days, Faye explains that she *was deaf… the deaf girl* and Caroline similarly describes herself as *just hard of hearing.* Mike associates being younger as a time *when I could see,* but reports that *now, I'm blind now.* Although now all deafblind, at certain points in their interviews, some participants continue to describe themselves as single sensory impaired. Reflecting their cultural affiliation, Anthony and Celia positively describe themselves as *Deaf.* Celia proudly shares this identity with her friend and maintains it in her description of being a parent:

> *Yes, profoundly Deaf. Strong BSL user, the same as me (I) (18.40).*
>
> *She went to the Deaf club, and I knew her… And [Person E] knew me, and that I was a Deaf mother (I) (22.9-15).*

Matthew, Caroline, Phillip and Mike all define themselves as *blind*. Data indicate that legal processes are important here, as participants often refer to their status as individuals who are *registered* blind. For Faye, such registration confirms the impairment, providing evidence to others that *it's not something I'm making up.*

At other points in their interviews, participants do define themselves as *deafblind*. The sense of multiple identities is made explicit by Celia, who describes herself as *disabled* then signs *I'm Deaf, I'm blind and I've got Usher.* Although at some points in his interviews Matthew describes himself as *blind* or *deafblind,* he also appears to reject these as identities:

> *I'm basically normal, even though I've got a sight and hearing problem (18.32)*

Caroline similarly explains how she does not *see [herself] as deafblind*, describing the term as *very emotive* and *too total.* She adds that one of her desires in later life is *not being seen as deafblind.* However, this creates a sense of confusion in her identity, as the following extract illustrates:

> *I'm thinking, I'm getting confused… I get confused about whether I am a deafblind person or not. I know I am, but I think I'm not. So, I'm not quite sure what to be… I'm not sure who I am (37.35-38.18).*

Getting older and perceptions of old age itself also have a role in the participants' interpretations of their identity. Designating old people as a chronologically defined discrete group, some participants describe being old as unknown, because it is a time of life not yet reached; this is particularly apparent in the interviews of participants aged in their late 40s or 50s. Nevertheless, Anthony, in his 70s, laughs as he declares *I'm not old yet.* Faye presents as more ambivalent, as revealed in the change of tense used when describing her younger self and the tentative reflection on whether old age has been reached:

> *I was, I'm still quite young so I don't think I've reached [pause, shakes head] (20.26-7).*

For Mike, old people are not only chronologically defined – *people older than like 60,70, 80, 90* – but also as people *older than myself.* Not seeing himself as an old person appears to influence his choice not to attend a particular deafblind social group:

> *I didn't like it very much, so I don't go any more… Because it's a bit, it's a bit, it's for old people really (26.47-27.2).*

It appears that for Caroline, getting older exacerbates the confusion she feels about her identity. Aged in her mid-twenties, increased sight impairment in old age had been foretold when she received a retinitis pigmentosa diagnosis and was advised that *you should be able to see quite well until at least you're old.* Now in her late 60s, Caroline still has some useful residual vision. She therefore now questions her identity as deafblind, even to the point of feeling guilty:

> *I'm not like most other Usher people that I've come across, because I can see and read… How have I got to this age and still being able to, to do this? And I feel guilty because I can… And I feel that I shouldn't be able to… it's just very weird (37.36-38.39).*

Rose explains that for her, old age and deafblindness *merge into one*. Consequently, in relation to her own sense of identity, and how she imagines others to perceive her, the deafblindness diminishes, as she becomes *just another little old lady.* Caroline similarly reports feeling that *people just see you as somebody old.* While to an extent this reduced identity is lamented, it is sometimes seen as positive. Acknowledging that *everybody* *gets older*, Matthew explains how negative experiences of exclusion earlier in his life may be visited upon those doing the excluding as they get older: *it will probably bounce back on them.* In the following extracts, Rose describes, how now older, she is no longer the odd one out among her family and friends:

> *It's different now… there's a joke about it, well it's not funny, but the, the situation now is that my sister doesn't hear very well (13.18-9).*
>
> *But I have become, I'm very aware of the fact that most of my peers, or shall I say most of my friends… err have a disability of some sort… It wasn't always so in the past… But it's become increasingly so now, as other people, as they age, do have disabilities that perhaps didn't have before (64.5-11).*

8.2.3 Experiencing deafblindness as multi-faceted

As described in Chapter One, being unable to use one sense to compensate for impairment in the other is considered a defining feature of deafblindness (see section 1.2.1). Although, as noted above, participants often talk about their deafness and sight impairment separately, it would be inaccurate to suggest that they do not also describe the combined effects of the condition. When they do, the inability to compensate is, in Caroline's words, the *game changer*, distinguishing deafblindness from single sensory loss: *if I didn't have both the hearing and sight impairment, I could do anything.* Rose explains how the *difficulty is when you can't compensate*, which is a consequence of the fact that *one [impairment] hinges on the other.* This affects her ability to engage in social activities, as illustrated in her experience of a church discussion group:

> *And I was getting very frustrated, because I couldn't hear what was being said and I couldn't, I couldn't, obviously couldn't lip-read, or, err, and, and couldn't also couldn't catch people's eye (65.4-6).*

By comparing her impairment with others, Caroline similarly describes how the extent of her impairments has reached a point where the inability to compensate affects her receptive communication:

> *… if somebody has better sight than I have, or better field of vision, they can lip-read better. Or if their hearing hasn't gone down as much as mine, they can hear them without having to decipher what they're saying (12.44-7).*

An inability to compensate is also associated with mobility difficulties, as Mike explains:

> *I can hear the traffic but I can't see to cross the road (3.32).*

For Faye, it is the impact on the ability to compensate that leads her to define sight loss as *the worse thing that can happen to a deaf person.* Nonetheless, data indicate that it is not only the dual nature of their sensory impairment that creates difficulties and frustrates participants' ability to compensate. Other situation and setting specific elements, such as the environment, including the location of road crossings, the actions of others, the design of equipment, or a combination of these are contributory factors. It is in these situations and settings that participants' describe experiencing deafblindness. For example, Celia, Matthew and Rose all describe how differing light levels impact on their ability to mobilise safely, particularly when coming indoors having been outside. Caroline explains how low levels of light affect her receptive communication: when combined with her reduced vision, they make lip-reading impossible. If outdoors with her husband in the evening, she *can't see what he's saying.* For Celia, limited light adversely affects her ability to compensate in relation to her expressive communication, as shown in the following extract in which she describes being unable to ask for help when lost outdoors:

> *Because it was dark, it was half past four, it was dark, and I couldn't make people understand what I was saying nor them replying. No point writing it down (I) (15.42-44).*

Illustrating the role of lighting levels in the experience, rather than just her deafness and sight loss, this is contrasted with her later experience when indoors:

> *I wrote it down on a piece of paper and gave it to them. There was a light, so I could actually write it down (I) (16.32-3).*

Matthew recalls being able to go to the local town centre alone *quite happily*, irrespective of his impairment. However, he now describes no longer feeling able to do so, because of *people running around everywhere, and pushchairs going about 90 miles an hour, and buggies all, all over the place.* Phillip similarly describes how obstacles such as *chairs and tables* complicate his ability to mobilise safely. For Faye, both changing light levels and obstacles negatively impact on her experience of using public transport; she experiences deafblindness as she finds herself in her *own bubble*:

> *...getting on and off buses, it's a different light condition inside the bus to outside the bus, erm... I don't seem to be able to look...you're sort of in your own bubble sometimes... just checking where the pushchairs are, children, erm, because they tend to be out of your peripheral vision... people who pull those little suitcases along (10.32-47).*

Even inclement weather can contribute to the experience of deafblindness. Rose explains how she dislikes going outdoors if it is raining, as rain drops on her spectacles and the shininess of a wet road surface make it *actually harder to see.* In the following extract, she reflects on how environmental factors spoilt her enjoyment of an outdoor exhibition for the public, put on by the emergency services:

> *But because I was standing where the wind was blowing in the opposite, blowing the sound away, I couldn't hear it. And of course, I wasn't near enough to actually see it in detail either… And I thought [pause], in one way I thought, 'Well, why am I here anyway'… there's so much I miss out on (53.23-38).*

Environmental factors also diminish the effectiveness of Celia's attempts to mitigate the impact deafblindness has on her enjoyment of outdoor excursions. Owing to her condition, Celia explains how she uses her residual vision to monitor the ground below her, thus making it impossible to enjoy her surroundings. She begins to use a wheelchair to remedy this situation, but uneven pavements lessen the helpfulness of this strategy:

> *I've always looked down at my feet, making sure the ground is level. My daughter has noticed that. She asks, 'Have you noticed anything around you? Did you see that in the corner? I look around but miss things because I'm looking at the floor. Thought it would be better to have a wheelchair… I felt relieved, I can see around… The wheelchair is good, but on the pavement, it's very bumpy. It makes it difficult to see because my eyes vibrate (I) (12.2-11).*

Participants also interpret the actions of others as contributing to their experience of deafblindness. Mike, Matthew and Phillip all describe having difficulties with receptive communication owing to the interlocutor failing to increase the volume of their speech, and Celia reports having difficulty lip-reading non-Deaf people. In noisy settings, such difficulties are exacerbated. Mike recalls how his compensatory use of touch when shopping is frustrated by retailers' rules:

> *… when I buy them, then I can feel them, but before you buy them you can't touch them in the, in the shop (47.5-7).*

By contrasting two encounters with individuals at bus stops, Caroline illustrates how a combination of factors, including environmental elements and the actions of the other, contribute to the experience, or not, of deafblindness. In the first, a noisy environment and the other individual's behaviour, render receptive communication impossible; in the other, a quieter environment and the other woman's clear voice and proximity, demonstrate to Caroline that when *the conditions were right, I could have a much more enjoyable time:*

> *Actually there were two situations, one where it wasn't a problem and one where it was. Erm, the one where it was a problem was if I was waiting at the bus stop and erm, there was another woman waiting and she started talking to me… I've no idea what she was saying, so I just smiled and whatever, and tried to lip-read her, but she kept turning her head away because she was looking to see if the bus was coming… But on another occasion, the only one I can ever remember having a conversation with somebody at a bus stop, erm, she had a very clear voice, she was sitting quite close to me, it was quite a strident voice, and there wasn't much traffic at the time… So I knew the contrast, I knew and it still sticks in my mind that if the conditions were right, I could have a much more enjoyable time, with complete strangers, than, that I do… I would like just to exchange the time of day with somebody and then just go on my way. And I can't do that (9.15-10.12).*

Comparably, Celia explains how the lights fitted to her front door, in combination with others' actions, ironically diminish rather than enhance any sense of security: the positioning of both the lights and the caller contribute to her experience of deafblindness in that situation and setting; the door is *not suitable* and is closed to the visitor:

> *That door, there's a light, a PIR light, there are two. I open the door to someone, it makes the face dark. I tell them, 'Please can you move back', but they won't… I won't let them in… The person talks back and we ignore each other. I close the door… If I put the chain on the door, the same, same. (I) (8.28-32).*

8.3 New Challenges and Increasing Difficulties

All participants describe new and increasing difficulties as they get older, and these can have an impact on their lives and their well-being. The interaction between ageing and deafblindness complicates and contributes to these challenges, impacting on the participants' perception of old age and engendering, in some, a fear of getting older. Although it is evident from their interviews that ageing with deafblindness enables participants to 'get used to' the challenges they face, data indicate that the experience of 'getting used to' has its limitations.

8.3.1 Ongoing and increasing difficulties as ageing

Describing life with deafblindness as *sometimes like a minefield*, Matthew observes that *life has got a lot harder.* When asked how he copes with it, he pauses before responding:

coping with it, is, is not easy. Other participants similarly describe life as *very difficult, harder* and *really hard work now getting older,* and Mike laments that he *can't do things like I used to*. Although not always encountering substantial difficulties, Rose explains how challenges *are happening all the time.* For Faye, as she reflects on *what I'm up against,* she physically enacts her sense of increasing difficulties as she ages, which she describes as *closing in on* her:

> *I know how I feel now is different to how I felt five years, ten years ago, and it, it's not a nice feeling, feeling it sort of growing [moves hands over her head] if you like and not growing for the better. Erm, it is getting harder and your, you know, you feel the, it's closing in on you [moves arms in front of body]. And erm, it's not nice (18.14-19).*

As shown in the previous chapter, participants explain feeling less able to withstand challenges now that they are older, and fear they will increasingly be seen as incapable. Participants also describe being *more isolated now* and *becoming very lonely*, and refer to continuing difficulties with indoor and outdoor mobility, and communication, particularly in social situations. Matthew reflects on his difficulties accessing formal care and support services, *even at my age*, noting how this has been an ongoing challenge throughout his life:

> *Because it was not offered to me when I was at school, when I was at college, when I left education [pause], and no, it just wasn't there (30.35-6).*

Associated with increasing difficulties, Rose finds herself standing out *as being more needy*. It appears that increasing difficulties are accompanied by participants making new requests for support. Both Anthony and Celia explain how they now have to ask people for support more frequently, and Mike explains that although he *used to make* his own meals, this is now something *the staff do.* Data also reveal that the cumulative nature of the difficulties participants encounter throughout their lives can have a negative impact on their well-being. Caroline explains how she needs to be *constantly alert,* carefully looking around and questioning what she hears. Faye similarly describes having to *concentrate* and *look out,* resulting in a need *to be on top form all the time.* She explains how this is *wearing* and stressful:

> *...when I'm moving around, I have to double check all the time and it, it, it's more stress that I feel as a result of the disability... certainly on a day to day basis (10.30-2).*

Faye adds that this need to be constantly alert leaves her feeling that her deafblindness is something she could *just do without*; a sentiment echoed by Caroline as she withdraws from a social encounter owing to communication difficulties: *I just thought I can't be doing with this, and I just didn't bother.*

The impact of ongoing difficulties is perhaps most strongly expressed in Phillip's telling of his experience of difficulties at work. He describes feeling that his *limitations* at work were misunderstood, having difficulties mobilising safely around the office, and being placed in an inaccessible environment. An unhelpful gesture by his manager is the *last straw:*

> *I cracked up, I couldn't cope… I finally collapsed, nervous and sheer exhaustion (35.21-30).*

The emotional impact appears important. Caroline describes how she *would be out there… driving the car and going places* it if were not for her deafblindness, and it therefore *kind of spoils contentment.* For Mike, even where his ability is unaffected, his deafblindness negates enjoyment, as illustrated in the following extract in which he comments on his water sports activities:

> *I can still do it. But when I could see I used to like it. But now I can't see I get fed up. (46.48-9).*

8.3.2 A complicated interaction: ageing and deafblindness

While, as Caroline explains, difficulties develop *over the years,* data indicate that being older itself can complicate the experience of deafblindness, and *vice versa.* It appears that participants interpret their existing impairment as compromising their ability to manage getting older, and getting older diminishes their capacity to manage their deafblindness. For example, although feeling increasingly isolated, Caroline explains how it is now *harder to make the effort* to engage with people. Exclaiming that *getting old is scary*, Faye reflects on how her deafblindness is an additional difficulty *on top* of old age:

> *… my parents didn't have hearing or sight problems, but you know they struggled with old age, and I know that [pause] I've got that on top, as well (2.42).*

She later adds that already having deafblindness engenders a sense of accelerated ageing:

> *I feel that I've got old before my time because, erm, old people do tend to lose their sight, lose their hearing, and I've already reached that (20.22-4).*

All participants tell of further deterioration in their hearing and vision now they are older (see section 8.4.1); in Mike words, *well since I got older, it's gone worser (sic).* This may be the result of late manifestations of the original aetiology or the emergence of new conditions. Rose and Faye describe becoming increasingly aware of their deafblindness, now older; for Rose this is despite the fact that *I always knew that I couldn't see very well and… I was aware of my hearing.* Participants also describe developing additional health problems, now older, including physical and mental health difficulties. For Anthony, old age is unequivocally linked with physical decline, emphasised in his assertion that he has not currently reached *true old age* because he is *not frail yet*. He describes feeling *more tired*, less strong, and states that *age causes* him *various pains within the body*. In separating his physical self, Anthony simultaneously claims that he is *not old yet*, while acknowledging that *my body's getting older*. In responding to such physical decline, Anthony notes the role his deafblindness plays in limiting the information he has to manage the process:

> *There's lots of risks, I have to take medicine and things like that… when deafblind people are old, maybe they need someone to support them… go to the doctor's with and talk… explain what's going on… You kind of almost need a doctor to explain what getting old is, and have that done through a guide or interpreter (I) (15.49-16.40).*

Rose similarly describes how a lack of access to information impacted on her ability to manage her diabetes, and believes this resulted in the condition deteriorating and the development of anorexia nervosa. As such, as Rose explains, it appears that such additional problems and deafblindness *don't go very well together.* For Phillip, deafblindness problematises the way his additional health problems are managed and his additional health problems (electromagnetic hypersensitivity) affect how he manages his deafblindness, as the following extracts illustrate:

> *I had all the problems at the mental health hospital, because they didn't understand about my, my eyesight (39.28-9).*
>
> *I go away, I can't have a vi, a vi, an electrical vi-, vibrating pillow, 'cos it's all electricity (37.9).*

Age related phenomena are also important in informing the way participants make sense of the effects of their deafblindness. These include retirement, changes of accommodation, an ageing network of support, and the appropriateness of care and support services. Faye describes feeling *too young to stop… working* but believes that although *most people stop working because of their age* she will be *stopped working because of my disabilities.* Although ultimately relieved on finishing work, Phillip describes being *forced out* of employment, having taken early retirement. As explored in the previous chapter, for Caroline, *things are a lot worse since being retired:* the resources employment offered enabled her to withstand the challenges associated with her deafblindness and are now no longer available. In the following extract, she explains how doing voluntary work *doesn't quite replace it:*

> *I would like the recognition that paid employees get, and the involvement that they get. And I know that can never be possible because that doesn't, just doesn't happen with the volunteers, you know, they're never going to be part of the workforce per se (26.29-32).*

Anthony explains how his move to sheltered accommodation *was really difficult.* It has limited his social life because of its location, far from public transport and his existing friends. Mike, Celia, Matthew and Rose all describe the impact that ageing has had on their network of support. This includes the deaths of family and friends, or their moving away to different locations. For Matthew, it is in the context of discussions during his interviews about his ageing parents that he expresses that he is:

> *… coming up to the age where I think… I really want someone to, to talk to me' (22.6-8).*

In the previous chapter, Anthony interpreted unsuitable support in mainstream older people's services as misunderstanding of his needs as a deafblind individual. Celia similarly expresses concern about the potential of mainstream older people's services to meet her needs:

> *… old people's home, I know I'd become very lonely, I wouldn't be able to have conversations with people, it would be difficult to write things down (I) (19.29-32).*

Nonetheless, she currently describes experiencing difficulties in her use of specialist deafblind services, as an older person, as illustrated in the following extracts:

> *There's nobody on there [Online Usher Support Group] the same age as me, they are younger (I) (28.39).*

> *I can't keep going out… I can't, four or five times a week. I can't do that and I think that's what [communicator-guide] expects. But I just want to go out once a week (I) (24.41-5).*

For some participants, such challenges as described above, appear to engender negative perceptions of old age. For younger participants, additional increasing difficulties in later life are expected and feared:

> *Faye: so you know that, that getting old will be hard (2.46); I know that I will not have an easy time I don't think (20.1-2).*
>
> *Matthew: And for the future [pause] it's not gonna be easy (67.1).*

Later life is described as a time of lost independence, increased sensory loss, additional health problems, physical decline, and feelings of *resentment* and worthlessness. Despite ongoing difficulties accessing formal care and support, Matthew wryly observes that much later life will trigger such access:

> *I don't think I'm gonna get help for doing X, Y, and Z, until just before I leave this world for the next (59.8-9).*

Notwithstanding these negative perceptions, several participants also describe old age more positively, suggesting that their views on later life are somewhat ambivalent. Both Anthony and Rose describe not *feeling old* and Matthew uses an oft quoted phrase when asked about becoming older following a recent birthday: *It's just, just a number.* Unlike Caroline, he goes on to express a desire to live a long life, which is presented as something of a blessing:

> *If I'm fortunate, if I'm fortunate, I could be living to at least 70 or 80... Or even 90 if I'm lucky (78.4-33).*

Participants also understand later life as a time of increased experience and reflection. Rose is capturing her reflections by writing her autobiography, which she explains has been *good for* her, enabling her to revisit difficult times in her life and respond to them differently (see the next chapter, section 9.3.2). It appears that for Faye, getting older is something of a turning point. Having described missing out in earlier life because she has *taken the easier path*, getting older is a chance to *change the way you think* and embrace the life one desires:

> *getting old... it's kind of an opportunity [pause] to start thinking... a little bit of a wake up call, and when you sort of consider what you want from life, you know... it is a time to contemplate... what do you want from life (2.49-3.16).*

It is apparent in the interviews that participants are engaging in a range of activities now in later life. They describe volunteering, learning new skills such as bowls and Tai Chi, learning how to use new technologies, and making plans for major events, such as travel overseas. Anthony explains how he recently learnt to check his bank balance using his mobile telephone, and Celia, the oldest participant, excitedly tells of her use of iPhones, iPads and WhatsApp, to maintain connection with family and friends online. An understanding of older age as a time of development and potential is perhaps most movingly illustrated during Anthony's final interview, when he presents his painting of a waterfall. Describing it as being about his life, he eloquently explains its meaning:

> *It's mostly about the movement and life being full of movement [pause]. Waterfalls flow and they don't look back that are always moving forward. It's about the potential, the energy moving forward... It's a feeling, movement, movement... But it can be smooth or rough. It's always going onwards. So they go down, but they still continue forwards, and they never go backwards, always pushing ahead (51.36-52.9).*

8.3.3 Getting 'used to it' as limited

Ageing with deafblindness means that participants have lived with the impairment over a long period of time. It appears that, for some, they have therefore 'got used to' the impairment. In Rose's words, she is *used to it in the sense that it's familiar.* Participants also explain how they are able to manage certain tasks because they have got used to it. For example, using public transport is unproblematic for Matthew because he is *used to getting on and off buses.* Rose similarly describes getting used to using public transport, joking that if she *couldn't cope with that now, there's not much hope.* 'Getting used to' also appears to reduce Mike's fears of being unable to identify the location of sounds and Matthew's success in using new equipment: *eventually you get it right.*

Nevertheless, the extent to which participants 'get used to' the impairment and associated difficulties is limited. Again using Rose's words, *I accept it on one level, but on another level [pause] it's not too easy.* An emotional rather than practical experience is important here. In a poignant moment, Caroline expresses a desire to end her life when she feels she has simply *had enough* and fears that she will never get used to feeling aimless in later life. Celia explains with sadness how deteriorating vision is *awful, awful* albeit that its been happening *for a long time.* In the following moving extracts, Caroline and Rose explain how they do not get used to things emotionally, in relation to being misunderstood, changes in vision and being excluded in social situations respectively:

> *Caroline: I'm used to it. It, it makes me a little bit sad (11.10-1).*
>
> *Caroline: I think I probably would adjust. I'd just get a little bit more sad about it each time (21.10-1).*
>
> *Rose: I understand how this happens, and why it happens. I never get used to it, I still find it very hurtful (32.15-6); I don't, I haven't got used to it in the sense that it's just as painful (78.46).*

8.4 Experiencing Change and Making Adaptations

Faye describes ageing with deafblindness as *quite a weird process.* The final superordinate theme shows how participants experience change as a continuous part of this process. All participants, including those with congenital deafblindness, focus in particular on changes in their hearing and vision. Data indicate that participants interpret some changes as an indication that certain benchmarks in the process have been reached. In response to change, participants explain how they need to adjust and readjust, by, for example, learning new skills or compensating for loss. However, the need for others to similarly adapt is also described.

8.4.1 Ageing with deafblindness: transition and change

Participants describe experiencing changes early in their lives and for Celia such experience is all encompassing, as she exclaims *my life's changing.* Contrastingly, for Phillip, *it's minor things at the moment*. Nevertheless, similar to other participants, the experience of change is ongoing. For some participants, change is experienced in the context of progressing through a broad transition: from young to old, from d/Deaf to deafblind. As outlined above, Faye presents as ambivalent about whether she has reached old age, and although Anthony states *I'm not old yet,* later in his interview, he signs *I'm not young.* Phillip is hesitant as he struggles to define himself when asked if he considers himself old:

> *Middle, err, err, senior middle aged [smiles] (9.48).*

Faye describes being *just a deaf person* and then becoming deafblind, a transition Anthony depicts as moving from one world to another.

Notwithstanding such experience of broader transition, it is change in hearing and vision that dominates participants' discussions. Interviews include descriptions not only of increasing awareness of such changes, but also their nature, which includes periods of stability and, for some participants, improvements as well as deterioration. It appears that this can engender a sense of uncertainty, as participants question whether and when their hearing and sight loss will deteriorate, as illustrated by Faye:

> *I, I don't know. When, how it's gonna happen (37.23).*

Experiences of deterioration in vision are common for those participants with Usher syndrome, owing to the nature of retinitis pigmentosa. Participants describe peripheral vision as *getting narrower, deteriorating* and eyesight *fading* or starting *to go bad.* Deterioration in hearing is also experienced by some, including Rose who observes that her *hearing has gone down… over the last what, 20 years.* Caroline and Mike explicitly describe experiencing deterioration in both vision and hearing at certain points in their lives. Some deterioration is associated with the original cause of the participants' deafblindness or late manifestations of this aetiology, such as cataract and retinal detachment (Celia and Rose). However, unrelated trauma resulting in further deterioration is experienced by Matthew, who describes how he *lost one eye, twenty years ago, after I had an accident.* While such deterioration is described as *constant* and occurring *over the years*, participants also describe some periods of stability:

> *Caroline: Having said that I don't think there's been much change in my hearing (40.40).*
>
> *Matthew: … but my right eye has been, has been fairly stable (5.22).*

In relation to her vision, Rose experiences concurrent deterioration and stability:

> *To a limited degree in the sense that, erm [pause] I haven't got any useful vision in my left eye now, erm, but it's, but my right is still about the same (16.21-3).*

Medical intervention is also important in the participants' experiences of change, as they describe improvements in their vision and hearing because of surgery or medical equipment. For example, both Matthew and Celia describe improvement in their vision as a result of cataract surgery. In the following extracts, Matthew explains how the development of hearing aid technology enables him to have the best hearing he has had *in any time of his adult life*; getting older is associated with improved not deteriorated hearing:

> *I've got up to date digital hearing aids, which are one of the best things I've ever had… I've had them not all that long and they're, and it's brilliant (5.30–34). / I'm hearing better now than I've had in any time of my adult life (79.46).*

As they reflect on the ongoing and constant nature of change, data reveal that participants expect further change, and notwithstanding the potential for improvement, the expectation is one of deterioration. For example, despite acknowledging that it is unknown whether her hearing will deteriorate, Rose *senses that it possibly will*, and irrespective of his positivity about new hearing aids, Matthew is categorical that neither his residual sight nor hearing will *last forever.* For Faye, this expectation of further deterioration is associated with an expectation of needing a high level of care later in life:

> *I don't want to feel, erm, I always have to have somebody with me, yet. I don't know whether that comes later, I'm sure it will (54.47-9).*

8.4.2 Ageing with deafblindness: a series of benchmarks

In making sense of their experience of change, participants interpret some changes as indicative that a benchmark has been reached. It appears that these are certain points, marked by new experiences or increased awareness of impairment, and they are not perceived as welcome. As Faye explains:

> *There's sort of, I don't know, err, lines in the sand, benchmarks, whatever, but you, you think, 'Oh that's new thing'… not very nice really… I'm not happy about it [laughs softly] (45.32-46).*

Although some benchmarks appear to be significant events such as retirement, indicative to Faye that she is *gonna run out*, it is benchmarks in the dual impairment itself that are particularly apparent in the interviews. For Celia, deterioration in her vision in the time period between interviews is observed, as she remarks on reaching the benchmark of no longer being able to read with both eyes:

> *Right, before when you were here the last time, I could read with both of my eyes. I could do that. But now, my right eye, I'm unable to do that. So I'm relying on my left eye. It's got much worse (I)(26.29-31).*

Noting that change *happens very gradually,* Caroline and Faye both describe increased awareness of their deafblindness as they reach a benchmark in impairment effects. Such experiences lead Faye to exclaim *Gosh, that's new:*

> *Faye: … like my husband, he's talking to me in the lounge, and err, he speaks so I turn to look at him and I thought he was sitting down but actually he's standing up. You don't realise till you turn round and you think, oh, he's not in the chair… You, you know, you didn't do that before… Err, I walked past my husband in the doorway once and I didn't know he was there and I thought, 'Gosh, that's new' (45.35-41).*
>
> *Caroline: I can be in a quiet room with my daughter, whom you'd think I'd be quite accustomed to hearing. She can be beside me; she can say something and I won't know what she's saying. It's loud enough and I'll say, 'What did you say?' or I'll catch the odd word. And err, I have to ask her to repeat it. That's not something that I think I've had to do all of my life, since I've been born (45.16-21).*

For participants with Usher syndrome, their sight loss is marked by a series of benchmarks, or in Phillip's words, progression *beyond a certain point.* For Anthony and Mike, this process ends when they become *blind* or *fully blind.* As she gets older, Faye interprets her sight loss as reaching certain points at different times in her life: knowing *something is not right* in her early teenage years; experiencing *problems* in her late teens; starting to *impinge late in my life;* and then, a sense of it *sinking in* as she acknowledges, *oh yes, it's happening now.* It appears that her first experience of falling is also another benchmark reached, as she responds to the comments of a passing stranger about falling over being a shock:

> *I don't know whether it's a regular occurrence for her, but it was the first time that has happened to me (45.16).*

Data indicate that increased and new problems are also benchmarks. Participants describe reaching a point when they can no longer read print on a computer screen, look at a closed circuit television screen, and read television subtitles. For Rose, she describes her deafblindness as:

> *… coming to the point where, yes, I do miss out a lot, and I worry, and I already miss out a lot in what I see (73.40-1).*

Reaching such benchmarks is associated with needing assistance. For example, Celia expresses relief that her daughters came to live with her *at the right time, when it got worse* and Phillip explains how, after a period of struggling, he needed to make use of Access to Work monies to fund adaptations at work *in the end.* Nevertheless, by continuing to do tasks independently, reaching some benchmarks is postponed. For example, in discussing a possible move to using deafblind manual in place of reading print on her iPad, Celia signs:

> *I'm not ready for that yet. If I can do it myself, that's fine. I can read when I want' (I) (5.1).*

8.4.3 Ageing as ongoing adaptation and adjustment

Participants describe how they respond to change by making adjustments. This includes adjustments at work, adjustments to coping strategies, and adjustments to changes in hearing and vision. For Phillip, adjustment is interpreted as central to the experience of ageing:

> *Getting old? Erm, having to readjust and adapt to, to different changing circumstances, it's very difficult (8.17-9).*

Adjustments to enable communication are made in various ways. This includes adapting an existing language/communication method, principally for receptive communication. For example, Celia describes changing her receptive communication modality: from British Sign Language to tactile (hands-on) British Sign Language. This necessitates not only a change in receptive communication but also reduces her communicative interaction to a one to one basis. Nonetheless, it appears such adaptation is perceived as positive, as she feels *much better with that.* Participants also describe learning new skills, such as braille and touch-typing, and begin to make use of technology. Over time, developments in technology not only facilitate adaptation, but also guide it, as Rose explains:

> *Well it [communication] has changed in so much as technology has changed it.... Now I type. Also, I've got access to e-mail (68.28-37).*

However, Celia describes adjusting the way she uses technology in order to meet her particular needs:

> *My iPad is OK. I have to turn all the lights out to see it. It's fantastic (I) (29.44-7).*

As participants adjust to changes in their hearing, they similarly need to adjust to changing hearing aid use and hearing aid technology. This includes moving from one hearing aid to two, changing from analogue aids to digital aids, using new types of hearing aids, and learning to use a hearing aid later in their lives. For example, although congenitally deafblind, Rose did not use hearing aids until she was in her early 30s. The ongoing nature of such adjustment is illustrated in Matthew's normalisation of very regular audiometry:

> *I've only had four hearing tests since I moved here (19.49).*

Environmental changes also prompt the need for adjustment, often supported by others. For example, Phillip describes needing to arrange additional mobility training from a rehabilitation officer when his *route needs change* because *they've moved the post office.* Matthew comparably explains needing mobility support when changes are made at his gymnasium:

> *I had to have a complete tour round the gymnasium so I know where everything was… when they decide to change things, I'll need another guided tour around the building (55.29-56.14).*

Data also indicate that participants adjust by compensating for loss. As they get older and experience increasing hearing and sight loss, participants describe having to *take my time, go slowly* and be a *bit more careful.* There are also specific examples in the interviews, of participants finding alternatives in response to changing needs. For Anthony, this is key to coping with his isolation:

> *I learn how to cope with my isolation… I try and think, what can be altered, what an alternative might be. I try to find whatever's like an alternative to the challenges (I) (5.1-3)/ You have to find alternative ways to kind of engage with the world (I) (14.17).*

Mike and Anthony both describe making increasing use of touch to support their engagement in hobbies, and Phillip explains that because he *can't walk, run* alone, he uses an exercise bicycle at home. He also describes having *to adapt* by finding *other ways of getting to the [charitable group] meeting.* In the following extract, Celia illustrates how accessing the online Usher support group enables her to compensate, as she reads about the travels of other group members:

> *They go far. They've been to [name of two cities]. I can't travel far, but I can read about it and that's perfect (I) (28.42).*

Although adjustment can be planned, it is apparent that participants become adept at adjusting in the moment. In Phillip's words, *some things happen un-, un predictable, so you have to make changes then.* Celia, for example, describes quickly moving to writing things down on paper if she is having difficulty lip-reading, or her interlocutor cannot understand her expressive communication, and Anthony engages in individual level adjustment in each social encounter:

> *I learn from each person, each different character, and each different communication. It's that social interaction that I adjust, I adjust, to try and make the relationship on the same level (I)(5.38). / I just think about how to help to find the best way to help that interaction (I)(8.17).*

In describing their need to make adjustments, participants reflect on how others must also adjust. For example, when discussing his earlier work life, Phillip explains that his employers *had to adapt and I had to adapt, as time went by.* Anthony observes such need in his social interactions:

> *... maybe I frighten some people, they sometimes have to calm down and adjust to feel comfortable with me [laughs] (I)(5.43-5).*

When others adjust, it is positively received. Rose considers her doctor as *very, very good* when he wrote things down for her during an appointment that *worked very well*. Nevertheless, participants describe experiences when others have failed to adapt. This is not necessarily another's unwillingness, but rather forgetfulness owing to the ongoing nature of change. This is illustrated in the following extract, in which Caroline reflects on family life:

> *I think I have to adjust and I have, I would like to expect them to recognise it but I don't think they do, so I have to ask them to adjust. So I suppose my family's adjusted to the fact that I can't see at night, so they help me more if we ever go out at night, which I don't much. And my husband tries but he doesn't remember [chuckles]. He's not very good at remembering things, so if you ask him to, erm [pause], what do I ask him to do, yes moving, moving glasses, putting them, not just leaving them anywhere over the kitchen work surface, to put them at the back near the sink. He will remember a few times, and then it will gradually slip again, and he'll, he'll start forgetting... Erm, but otherwise, sometimes I, I get quite annoyed, look I just can't do this, you'll have to, you have to realise I can't see, do this, et cetera. Erm [pause] yeah there, there, it just, it just as each situation, if we're in a situation where I need him to make allowances, then I can apply it, I can ask them to help me in that situation but it doesn't really necessarily mean they'll remember for the next one (39.22-43).*

8.5 Conclusion

This chapter presented findings related to participants' interpretation of their experiences of ageing with deafblindness. In the analysis of the interview data, three superordinate themes were identified. The first of these shows how participants understand their dual impairment and how this contributes to a sense of multiple identities. Data also reveal that although participants experience deafblindness as difficulty compensating, such difficulty transcends the inability of one sense to compensate for impairment in the other and is multi-faceted; situation and setting specific elements are contributory factors. The second and third themes proffer direct challenge to notions of life-long conditions as easier to manage and sensory impairment as static or stable. Participants experience ongoing difficulties as they age, and deafblindness and ageing complicate each other. Change is a common experience for participants, and changes in hearing and vision dominate their discussions. In response, participants make adjustments by, *inter alia,* learning new skills and compensating for loss. Nevertheless, such adjustments may be rendered nugatory if required adjustments are not made by others.

Notwithstanding the challenges associated with ageing with deafblindness and the ways in which others' responses contribute to participants' felt vulnerability, as described in Chapter Seven, it would be inaccurate, and unsupported by the data, to suggest that participants lack agency or are passive actors in their experience. Analysis of the interviews reveals the many ways participants actively manage their vulnerability and experience of ageing with the impairment. These are explored next, in the third and final findings chapter.

CHAPTER NINE - FINDINGS: MANAGING AND COPING

9.1 Introduction

As noted in Chapter One, although contemporary thinkers have developed positive definitions of vulnerability, the phenomenon has exclusively been conceptualised as negative in the context of health and social care (see section 1.4.1). Some participants in this study acknowledge that their avoidance of situations in which they feel or have felt vulnerable has reduced opportunities available to them (see Chapter Seven, section 7.2.4). Nevertheless, all participants understand vulnerability as primarily negative. Notwithstanding this interpretation, and the lack of a salutogenesis perspective in the deafblind literature (see Chapter Two, section 2.8.2), participants do not present as passive individuals: they are active in responding to and managing their felt vulnerability and the challenges they face.

This final findings chapter explores how participants make sense of their experiences of managing and coping with felt vulnerability and ageing with deafblindness. Three superordinate themes were identified: taking action to protect self; psychological coping strategies; and accessing and using care and support. Although participants describe learning from others and asking for help, the first two themes show how they develop, often creatively, their own solutions to challenges encountered. These involve both practical actions and psychological strategies, and address elements they identify as generating felt vulnerability, as considered in Chapter Seven: being and feeling misunderstood; feeling unable to withstand; isolation; lacking the full picture; losing control; and being perceived as incapable. The third superordinate theme describes how participants make use of both formal and informal care and support, and perceive this as welcome. In developing their descriptions, participants reflect on the positive attributes of both current care and support, and that desired in the future. These attributes appear to negate the impact of elements that contribute to felt vulnerability. As with the previous two chapters, findings are presented as a narrative account and use extracts from the interview transcripts to provide evidence for each theme (Smith et al. 2009). Where words contained in the interpretative accounts of the data are in italics, these are also the direct words of the participants.

9.2 Taking Action to Protect Self

All participants are active in seeking solutions, problem-solving and protecting themselves in vulnerable situations and settings. This can include taking direct action, such as cutting down over-hanging trees and branches to prevent them scratching one's face when walking outdoors, making use of a torch when going out in the evening, or being persistent in securing accessible information at a train station. Anthony explains that problem solving also requires him *to be creative* and there are instances of creativity and innovation in the interviews. For example, Matthew describes a *signalling pattern* used to indicate kerbs and other obstacles when being guided by his mother, and Phillip tells of a coding system he devised to manage his correspondence. Although each participant makes use of various strategies, data reveal shared approaches: telling, educating and challenging others; responding to and managing risk; maintaining connection; using reserves; self-care; maintaining control; and demonstrating self as capable.

9.2.1 Telling, educating and challenging others

For Anthony, educating others is *the gift of my deafblindness.* It appears that Rose assumes a sense of responsibility for doing so, as she declares that when it comes to telling of and explaining her impairment to others, she is *probably not as good at that as I should be*. In the interviews, participants describe telling and educating people about their impairment, their communication needs and how best to assist them. For example, when travelling by aeroplane, Anthony explains how he educates the cabin crew:

> *… tell the crew about communicating, about writing on my hand. When my food is here, please indicate that by tapping on my shoulder (I)(45.38).*

Interpreting these experiences, participants go on to explain why and how they tell and educate others. Data indicate that a primary function of telling and educating is to enable people to understand both the participant and deafblind people generally. Faye explains that she will tell people about her deafblindness, as she does not *want there to be any misunderstanding.* Telling others also appears to operate as a way of preventing the misinterpretation of behaviour. As shown in Chapter Eight, Rose has difficulty seeing in inclement weather, owing to glare off wet road surfaces and spots of rain on her spectacles (see section 8.2.3). She therefore chooses not to go out in the rain, but explains this decision to others:

> *I'm quite open telling people that, but don't expect me to be, to appear when it's pouring with rain… I say, 'I'm not afraid of the rain', I, I tell them why, exactly why… And people seem to understand that (18.40-9).*

Rose also describes having to explain in order to challenge people's disbelief about the extent of her impairment upon observing her behaviour. Unable to judge the height and depth of steps Rose focuses her vision on the sidewall, rather than the steps themselves, in order to descend safely. Observing her do so on a university campus, fellow mature students appear to question the extent of her sight loss, leaving her feeling the need to explain:

> *I was walking along, and, and, I got to the steps, and I turned to the wall, and looked [laughs]. And the, some of the students, my fellow students, were walking behind me, and they said, 'You didn't even look, watch where you were going when you were going down the steps'. So, I explained this all to them (80.28-32).*

Educating people can also ensure participants have access to the full picture. For example, explaining to airline staff how to meet his communication needs provides the full picture to Anthony when in an airport. He tells the assistant how to communicate with him, such that he is aware of the environment:

> *I sit in a wheelchair and the assistant comes and I tell them to sign 'S' [indicates writing S in Block on palm] for security, passport P, W for wait, things like that (I) (45.40-2).*

Telling others is something participants feel they *have to do*. In combating misunderstanding, it may be *the only way,* but can make a difference. As such, for Rose, although *there was a time when I wouldn't have enjoyed it much*, now older she is *not afraid to tell people*. Nevertheless, it appears that telling people once is insufficient. Phillip describes having *to keep on explaining myself to people* and comparably, Anthony laments that he has *to tell them again and again.* As such, it requires *lots of energy* and is both tiring and, dependent on how one feels, *annoying.*

Participants adopt different ways of educating others. Mike describes a previous role at a local education institution, teaching students about deafblind people and their communication and mobility needs. Phillip and Anthony have both sent out written information, published by specialist charitable organisations, to hospital staff and work colleagues; this material provides information about their condition, and their communication needs. Some participants tell individuals about their impairment, its extent, and associated needs directly, in specific encounters:

> *Rose: I always have great difficulties, as I've said before, recognising people outside… I ask people to, just to bear in mind that when they meet me out in the street or whatever, that, that they have to make the first move (27.17-25).*
>
> *Phillip: Err, at other times, err, I might just, erm… say, 'Look, you know, I'm severely sight impaired, not partially sighted. I can only see light and shade' (29.32-34).*

Phillip also makes use of visible equipment. This includes *waving* his red and white cane in the air, or more subtly, as the following extracts illustrates:

> *I'm in a restaurant, eating a meal in a café at lunchtime. Somebody comes up to me and says, 'Could you pass this over?' I said, 'What? What?'. 'Can you pass', you know, and then I go [rolls up sleeve and feels braille watch]. Don't have to say anything then [feels braille watch a second time] [smiles] (29.13-7).*

In some situations, participants not only tell but also challenge others, standing up for themselves and demonstrating their ability to withstand threat or challenge, diminishing felt vulnerability. Anthony remembers experiences early in life when he had *to be very determined* and *fight for myself*. Describing himself as *strong-willed*, he stresses that he *will not allow people to intimidate me,* and reports being *assertive enough to tell you what I think.* Caroline directly challenges a stranger who grabs her arms to offer unrequested help, by telling him to *get out of my space.* Rose similarly recalls the courage she showed when challenging her own parents about the support they offered, which was experienced as over-protection. This courage is also evident in the following extract, in which Rose describes chiding a member of staff at a railway station, who was unhelpful as she tried to purchase a ticket with a credit card:

> *Anyway, he, he would say, he kept saying things to me, which I obviously wasn't grasping quickly enough, and then he got really impatient and really, err, he said, 'I told you what to do that for' [mimics annoyed voice] and I, and at the end of it all, I said, 'Well, I don't think you've treated me very well'. I said, 'I am both sight and hearing impaired'. Erm, and I don't know what he said to that, but I don't think he said anything very much to that, but erm, I said, well I just said goodbye and that was it (38.3-15).*

Participants also challenge others by raising concerns or making formal complaints. For example, Mike raises concerns about staff with their seniors at the support accommodation scheme where he lives, and reports that this makes him *feel happy after a while.* Similarly, Matthew speaks directly to the organiser of social event he attended, during which he had been left alone. More formally, Anthony, Rose and Phillip all tell of times they have written letters of complaint, to airline companies, general practitioners, local authorities and charitable organisations.

9.2.2 Responding to and managing risk

Data indicate that participants' responses to and management of risk are important. This involves the identification of risks, consideration of the likelihood of harm, and making a determination as to whether taking the risk is *worth it.* In relation to being a victim of crime and falling, although being *always aware of these risks*, Rose considers them low probability. They therefore do not prevent her going out alone:

> *… it doesn't stop me wanting to go out on my own… I don't think, Oh dear maybe if I go… somebody'll trip me up and grab, grab my handbag, or something like that… obviously I'm aware of it, of the possibility of it. But it doesn't stop me from doing things…I haven't had any falls like that since I've been in [home town] (29.16-42).*

Conversely, recognising himself at risk of particular harms, Matthew describes getting a specialist smoke alarm fitted, which he *had to have done because of my sight and hearing.* Evaluating the level of risk of harm in his neighbourhood, which was *getting a bit rough,* he makes the decision to move house to avoid problems and expresses relief, stating *I'm glad I left at the right time.* Faye similarly evaluates risk in order to make decisions about travel:

> *I [pause] would not normally travel on my own at night, but there might be certain easy journeys that I would do… if I felt reasonably confident about the route (15.20-6).*

She goes on to explain that she is now *much more careful* when walking outdoors, particularly on steps and stairs. This involves slowing down, because the risk of bumping into things means being hasty is *not worth it.*

Anthony describes knowing about his *own safety* when travelling, and as observed in Chapter Seven, refutes the objective assessment of him as being at risk by others based on the inherent characteristic of deafblindness (see section 7.5.1). Demonstrating his own understanding of risk and frustration at the objective assessment by others, at the end of his second interview he sardonically comments on the interpreter touching him when engaged in tactual British Sign Language:

> *[direct to interpreter] I'm going to tell the police about him [interpreter] touching me [laughs]… [direct to the interpreter] maybe I'm at risk and should tell the police about the touching [laughs] (I)(39.35-41).*

Once risks are evaluated, some participants eschew certain tasks or situations as a way of managing them and avoiding or withstanding felt vulnerability. For example, going out at night, social events and certain culinary tasks are all avoided. Nonetheless, Faye interprets such an approach as *taking an easier path* and expresses regret that this has, on occasions, left her missing out on opportunities similarly to Caroline, for whom social isolation is increased by her avoidance of certain situations (see Chapter Seven, section 7.2.4). As such, her risk management strategy sometimes involves taking *some of those things a bit more face on*. In reflecting on the likelihood or severity of potential harm, she asks herself, *how bad can it get*, as illustrated in the following extract, in which she describes her decision to go out for a pub meal with friends:

> *… it was something that previously would have worried me, and yeah, it did worry me, but this time I thought 'well I'm gonna go out and enjoy myself'. I'm with friends, you know, how bad can it get? And erm, [pause] it, it, it was all really nice (16.43-7).*

Participants also adopt actions of a more practical nature to manage risks. For example, Matthew and Celia both explain systematically locking doors and checking the security of their homes each evening. Celia goes on to describe how she handles her money differently when with the communicator-guide as opposed to her daughter:

> *It's like with your bankcard. I'd prefer my daughter to the communicator-guide. With the communicator-guide, I always put my coins in the purse, and pay the bill and then put it away in my bag. But with my daughter, I don't mind, because I always trust my daughter (I)(20.16-22).*

Recognising the risks associated with physical contact (see Chapter Seven, section 7.4.1), Anthony explains how when he meets other deafblind people he *encourages* them to touch him. In this way, he manages the risks of both isolation and misperception or fear of physical interaction. This is illustrated in the following extract, in which he describes a visit from a deafblind friend, who was upset about never having been embraced by his parents:

> *So, I said I'll embrace him, and he got all embarrassed. And I asked why he was embarrassed, and he said he was scared; he was frightened of the law… and it's really very sad… But I think deafblind people can be frightened to embrace. That's why when I meet a deafblind person or a child, we touch… I encourage people to touch (I)(36.18-38.28).*

9.2.3 Maintaining connection

Although social situations are a setting in which participants can feel vulnerable, the maintenance of human connection provides access to information about the world and enables them to withstand isolation and felt loneliness. Anthony describes the curative effect of human contact, which is *like a medicine for loneliness* and helps him *feel part of the world.* Faye, Matthew, Anthony and Rose all reflect on the importance of their friendships, the person with whom they can talk things over; Faye believes that she will make a particular effort to maintain connection with friends once she is retired, as human interaction will not be available through work. Participants make use of mainstream technology, such as e-mail and mobile telephone text message apps such as WhatsApp, to stay in touch with friends. For some, this is used in conjunction with specialist equipment, such as braille output machines or speech software. Mike describes active engagement with the local Deaf club, which offers a sense of belonging, and excitedly tells of social occasions he has enjoyed in all three of his interviews. He also describes how receiving letters from a friend *makes me happy.*

For Anthony, physical contact is an essential part of human connection and is *very, very important*. Touch is described as offering *an image of a person* and enables him to *feel human* and *like a real person.* The importance of touch for Anthony is movingly captured in the following extract:

> *So, many times, when I am on my own, like [pause] food for instance, I get a food delivery, somebody carries the food and puts it in the kitchen, and they obviously have to hold my hand to show me where it is, and for a few seconds, it feels good to have that human contact… Even though it's just this short, short moment, it's good to have contact (I)(14.39-45).*

When he is alone, Anthony uses his artwork to maintain connection: *when I draw people, it's like engagement with people, I'm not isolated.* However, Anthony's ability to be highly creative is demonstrated during a particularly poignant moment in his first interview. He takes me into another room in his flat to show me a small statuette replica of Michelangelo's masterpiece *David,* and then explains how this artwork maintains physical, human connection:

> *So, you can see the statue. And you know many times I am on my own here, and I can't go out, and there is nobody here. What I do is, I have the statue [moves both hands over the statue, feeling it] and I can feel, and it helps me to feel human contact, through the statue, like touching a person… It's not a person; people might think I'm crazy… It kind of feels, well, I touch it [feels statue] and then I touch my own body [moves hands down torso] and it kind of feels like me… You have to find alternative ways to kind of engage with the world (I)(13.34-14.17).*

9.2.4 Using reserves

Participants describe drawing on existing reserves in order to withstand challenge and thus reduce felt vulnerability. Such reserves come in multiple forms, including prior learning and experience, residual senses, and activities that develop physical strength. Faye, for example, describes how previous experiences act as a *learning curve*, informing her approach to managing risk, and Matthew explains how at college he learnt *a few practical bits… that helped.* Anthony and Matthew describe acquiring attributes from their parents, which now support them in later life: resourcefulness, positive thinking, a sense of humour, self-reflection and forgiveness.

Participants with useful residual hearing and vision describe making use of this to access the full picture. In Matthew's words, *the little sight and the little hearing that I have got, I've gotta make the best of it.* It appears that residual hearing and vision is particularly helpful to Rose and Celia when they are outdoors and seeking to mobilise safely. When lost on one occasion, Celia uses her residual vision to help her find the police station, indicated by the *blue lantern*, and when crossing roads, Rose explains that she tries to *look and listen as best I can.* Caroline and Anthony, having been sighted in earlier life, describe making use of their visual memory. Now experiencing total sight loss, Anthony makes greater use of touch, as does Mike. In the following extract, Caroline illustrates how the expansion of her vocabulary though reading, now supports her lip-reading abilities:

> *a lot of that kind of, of understanding what's been said, depends on your own reading, the amount of reading you've done, your own vocabulary and how extensive it is. Because you do, you do a lot of gap filling (46.12-4).*

Phillip enjoys Tai Chi, which he does every morning. Although he explains that this has multiple benefits, both physical and mental, these benefits appear to act as a reserve that enables him to withstand difficulties encountered when travelling on public transport:

> *I have noticed erm balance, posture, circulation, and muscle tone is all improved…So, if I'm on a bus and the bus jolts, and I'm standing up, without smashing my head against something, falling down or something, I can reassert my body in such a way that I have control of my movements (54.44-55.3).*

9.2.5 Self-care

Owing to the stressful nature of having to be constantly alert (see Chapter Eight, section 8.3.1), Faye explains that you *have to look after yourself.* Data reveal that engaging in self-care is another way in which participants manage difficulties associated with ageing with deafblindness and withstand challenge. Reflecting their individuality, participants self-care in a variety of ways. This includes engaging in old and new hobbies and sporting activities, gardening, maintaining a sense of humour, and meditation.

Although Anthony and Caroline describe keeping themselves busy and their minds occupied, others explain how they take time out. With increasing sight loss, Faye describes reducing her hours at work to provide herself with a *breathing space,* and Celia occasionally asks her daughters to *leave me alone,* when she is feeling anxious or stressed about increased sight loss and needs time alone to *build up my strength.* Following a church discussion group at which communication was difficult, Rose recalls going out for a walk because she *just needed to get away from everybody.* For Matthew, metaphorically *switching off* enables him to withstand the fear he feels in hospital settings:

> *And I always take my, erm, MP3, plug in, plonk [mimes putting large headphones on] fine, shut out the rest of the world, cool (17.11).*

When making sense of his coping strategies, Phillip asserts that *it's the small things that matter really.* It describes the helpfulness of enjoying a drink, stroking his cat, or having a coffee. Mike similarly explains how having been in situation of felt vulnerability, he feels *happy again* when listening to music, having a hot drink or smoking a cigarette. It appears that the small things also make a positive difference for Celia. She enjoys having a glass of wine, and having been lost then anxiously finding her way to a police station, the impact of having a cup of tea while awaiting her daughter to come and collect her appears significant:

> *When I arrived and I sat down, I was surprised he could sign. I was relieved, we were talking, signing, and writing a little bit. He asked me if I wanted a cup of tea. I said, 'Yes please'… that's where I sat having my cup of tea. It was lovely (I)(17.38-18.8).*

9.2.6 Maintaining control

As reported in Chapter Seven, participants describe feeling vulnerable when they sense they are out of control, and identify losing control as something to which they feel vulnerable (see section 7.2.3.2). They express a desire to remain in control both now and in the future. In further interpreting their experiences, participants explain the ways in which they seek to maintain control in their lives. Data indicate that this is enacted through various means: taking things step-by-step; making and acting upon their own decisions; using care and support in their own way; and engaging in preparation and planning.

To manage the challenges of ageing with deafblindness, particularly deteriorating hearing and vision, participants describe addressing difficulties one at time: *crossing that bridge when we get there* or discussing it *when it's here.* Faye recalls a particularly difficult time when her husband was seriously ill, and this coincided with deterioration in her vision. To manage the situation she *just put one foot in front of the other.* Caroline appears to take control of her deteriorating sight and hearing loss, by driving the decisions associated with increased need for support:

> *I certainly don't ignore the deterioration of my vision or of my hearing…. I decided as well, I think I'd better start using the symbol cane. I decided we need to go to a long cane… I even decided that I would register blind… it was driven by, driven by me (40.44-41.14).*

Making and acting on one's own decisions are important ways for participants to maintain control. This includes making decisions on who to tell about their deafblindness, and where to go socially when making use of informal support. Although Phillip has assistance managing his correspondence, he stresses that he decides *what* *action should be taken.* In the following extract, Anthony demonstrates how he will challenge those who seek to control him, asserting that *it's my decision to talk:*

> *I'm never ever aware of my voice. If I'm excited, my voice is loud. Understand? Loud, excited, I don't know but people are always telling me to 'shhhh', keep it down. I like to talk to people, I don't want to sit and do nothing. Some people maybe get embarrassed. Anyway, so, I was talking to people, and it was difficult because she thought she could control me, and I said, 'No, it's my decision to talk to people' (I)(28.22-7).*

Participants also make their own decisions about the timing, the type and whether to make use of care and support. This includes choosing when to make use of equipment, contact health and social care services, engage with rehabilitation, and disengage from day services and social clubs. Maintaining control appears to inform Celia's decision to pursue human support rather than have a guide dog:

> *I think the dog, you'd take it out, it would stop, and I'd be thinking why? What? It can't tell me. So, I prefer a person to be with me I feel we're the same. Two people, if one coughs, I know. If the dog stops, you don't know why, if the human stops, you know why (I)(31.34-7).*

Rose similarly decides not to pursue a referral for a guide dog, but makes it clear in the interview that *it was my decision in the end not theirs.* Caroline asserts control by making her own choices throughout her life, even if these are deemed contrary to professional advice. She recalls refusing to wear a body-worn hearing aid when a child and rejects the use of red stripes on her long cane:

> *… people have said to me, well you're hearing and sight impaired, you must put red bands on it, and I think, 'No, I mustn't, it's my choice' (18.41-4).*

When participants do use care and support services, they do so in their own way. As Anthony signs, *I kind of put my stamp on them.* One way in which participants realise this, is by explicitly instructing those assisting them. This is illustrated in the following extracts, in which participants describe working with their communicator-guides:

> *Mike: I tell them, turn left, you turn right, and you walk down the lane (31.13).*
>
> *Celia: But just one thing, I don't want her to pressurise me to do what she wants. It's what I want. So, I've had that discussion with [communicator-guide] and that's fine (I)(24.7-9).*
>
> *Anthony: … so I'm the employer. I have to give them dates, times, a number of hours, rates of pay and invoicing, and make sure that it's clear and they understand. I decide everything. I tell you, you have to do it for me, you have to follow. You don't decide for me… It feels good, because I feel responsible… I never allow them to control me, no. When they work with me, then work with me, fine, control over me? No' (I)(24.39-29.9).*

Participants also use equipment in their own way. This includes holding magnifiers uniquely, combining specialist and mainstream equipment, and developing their own techniques that differ from those taught by professionals. For example, Matthew explains how he uses his long cane:

> *They [rehabilitation officers for visually impaired] taught me to use that. But, I use that, not the way they taught, because [pause] erm, because of my sight. So they say, tap it along the ground and all that [demonstrates using cane this way], I don't do that... I just, I just hold it, at an angle, level with almost, level, erm, at right angles like that [demonstrates positioning of cane] from the top to the ground... And it's the way I've always done it, and it works (7.6-19).*

Engaging in preparation and planning appears to help some participants maintain control. This can be preparation for specific short-term events or for long-term eventualities. Matthew and Anthony both describe how they prepare and make plans before going into hospital, either for an outpatient appointment or for a short stay. This includes doing 'test walks' to become familiar with the route to the hospital department, and preparing information on communication methods to share with health professionals. Without a plan, Anthony feels he gets *a bit lost really* and reports a need to *plan everything, to keep myself calm and keep problems low.* However, as observed in Chapter Seven, such preparations can be frustrated by the actions or omissions of others (see section 7.3).

Although he *takes life as it comes*, Matthew engages in planning for a time when his parents have died. He describes having *talked about it quite a lot actually over a little while.* Discussing the plans with his friend, his interpretation of the gravity of such preparations is revealed in his defining of such interactions as *summit meetings.* Having a similar 'take life as it comes' philosophy, Rose asserts that *we can't plan for the future* because *we haven't got any ultimate control over it.* Nevertheless, she has still prepared for the possibility of further deterioration in her hearing and vision, by learning alternative communication methods:

> *I've not actually had to use it [deafblind manual], but at least I, I know I could bring it into ac-, action if I need to (71.18-9).*

9.2.7 Demonstrating self as capable

All participants describe feeling vulnerable when and feeling vulnerable to being perceived as incapable (see Chapter Seven, section 7.5). It appears that all participants seek to contradict such perceptions by demonstrating their capability. This is enacted in the interviews themselves, as participants not only make broad statements about their abilities, but present as eager to tell me about their skills, talents and achievements. This includes providing a *good service* at work, being accomplished artists and musicians, having written work published, travelling and undertaking domestic chores independently, being economically savvy, and chairing charitable groups. Anthony boldly asserts that *deafblind can do anything like everyone else can,* and it is apparent that participants take a pride in their achievements. For example, reflecting on a time she supported her husband through a period of ill health, Faye observes that *it could have been quite easy to just have under with the strain* and she is therefore *quite proud of what I've achieved.* In making sense of the experience of getting lost, having boarded the wrong bus, Celia makes it clear where the fault lay, negating any notion that it is her who lacks competence:

> *The bus driver was stupid, because he forgot to change sign on the bus (I)(9.48)/ I'm not stupid. I know, I do know (I)(33.2).*

Participants also demonstrate their capability during their interactions with other people. Matthew challenges the assumptions of fellow gymnasium goers who perceive him as unable to use the equipment:

> *And I jump on the stuff and I think, oh yeah, fine, I'll do all that. And he looks at me and he goes, 'Oh God, he can' (69.45-6).*

Anthony explains that he needs to *convince* and *help people to accept my capability* and does so by physically showing them how he cooks, irons, makes his bed, and paints pictures. For Rose, having to prove to others that she is capable has been *a struggle with me all my life.* In the following extract, she explains how moving out of her parents' home to live independently was important in refuting their perception that she *couldn't look after myself:*

> *I had to start from scratch. But I managed to keep alive because I was so afraid, err, I managed to eat, so-, err, to [pause] to look after myself, because I knew I had to because I didn't, I want, I didn't want... Err, prove that, you know, that they were right, that I couldn't look after myself (10.28-32).*

In her qualitative study involving 27 deafblind individuals across six European countries, Hersh (2013a) shows that deafblind people are not only recipients of care, but also providers of care. Participants in the current study similarly demonstrate their capability by helping others, in a variety of ways. This includes leading community projects and volunteering for charitable organisations, and offering care and support on an individual basis. For example, Rose recalls supporting her lodgers, some of whom had mental health problems or difficulties associated with their immigration status, and Anthony describes how he gives other deafblind people *advice* and is *happy to help people*. For both Rose and Anthony, offering such support is understood as vocational.

9.3 Psychological Coping Strategies

In addition to the practical actions that participants take in responding to any challenges that they encounter, data indicate that psychological strategies are also adopted. For Anthony, these appear particularly relevant when no practical solution is available, as illustrated in his reflection on avoiding negative feelings:

> *There's no solution there, what is the solution? There's no solution, so why feel that way (I) (8.43-5).*

Akin to the practical actions, the strategies participants adopt vary, but appear to be centred on three approaches: accepting things that cannot be changed; changing one's own response; and demonstrating tenacity.

9.3.1 Acceptance of things that cannot be changed

Acceptance of things that cannot be changed emerges as an important theme. In reflecting on their experiences, some participants describe feeling resigned to things and having no regrets, irrespective of life's vicissitudes. Matthew makes repeated reference to *taking life as it comes*, stating somewhat stoically that he *could be here today and gone tomorrow.* Anthony presents a similar perspective visually, as he shows me a self-portrait during his first interview, and describes it as representing his life as both *beautiful and struggle,* yet *real.*

Acceptance enables participants to cope with different aspects of their lives: deafblindness itself; difficulties associated with the impairment; specific situations such as being alone, having to attend regular hospital appointments, and the reduction of formal care and support; getting older; and others' unwillingness to communicate. Anthony describes learning to accept himself, declaring that *I am who I am.* He explains that this has enabled him to accept others, seeing no one as perfect, and therefore avoiding a sense of blame when they misunderstand him or are unable to meet his needs: *I think I always try to understand that it's not people's fault.* Reflecting on her experiences of being misunderstood and perceived as incapable early in life, Rose comparably avoids blaming her parents and her school, acknowledging that *they did the best they could* and *it was nobody' fault.*

Rather than challenge people who have generated felt vulnerability or upset, Celia, Matthew and Caroline all tell of times when they have *let things go*. Mike similarly explains how he *just left it and didn't take any more notice* when represented as incapable by a member of support staff. Letting go may be immediate or come later in time. For example, after describing his difficulties at work, culminating in undesired early retirement over 20 years ago, Phillip adds that *it's a chapter that's closed, you, know… it has no bearing now.*

9.3.2 Changing one's own response

When making sense of his experiences of vulnerability, Matthew explains that he *was thinking of how I react to things and why I react to things, the way I do.* Although others' responses can create felt vulnerability (see Chapter Seven, section 7.3), data reveal that participants' own responses can influence the experience. For example, Celia describes *changing her way of thinking* when becoming distressed or anxious as she imagines further deterioration of her vision. Despite her concerns about the future being emphasised throughout the interviews, the impact of a change in thinking is apparent in her final reflection:

> *In the past, there was no awareness of Usher, but now it's improved, people try to help. So, the future, hopefully, that will get better for me (I)(44.23-4).*

Other participants also describe changing their ways of thinking, particularly negative thoughts about further deterioration in vision and hearing. They avoid over thinking or pondering on the matter, and *try to think about good things.* Both Anthony and Faye avoid thinking 'why me', as Faye explains:

> *... sometimes you think, 'I could just do without this', you know, just [shakes head] 'why, why do I have this' sort of thing, but, err, not too much of that (11.14-16).*

Reminiscing about negative experiences in her childhood, Rose explains how now, as an adult, she has seen them *in a different light.* This has enabled her to better understand these experiences and prevents her from seeing herself as at fault. For example, her perception of being something of a liability at school, is now interpreted differently:

> *... there was quite a lot of discrimination and what we would now call bullying, but we didn't, it wasn't recognised as bullying in those days... Erm but I realise now that's what it was (3.28-33).*

Participants also describe how changing their response in particular situations can diminish their felt vulnerability. For example, Anthony endeavours to *stay relaxed* at times of difficulty. He recalls a time when he was left alone overseas, following a disagreement with his communicator-guide resulting in her return to England. Staying relaxed and accepting it both appear important to Anthony, as he manages a situation within which he would ordinarily feel vulnerable:

> *I managed myself, I kept calm. I think it's very important to always keep calm and not panic. So, you just have to think things through. When she left me on my own, I just made different plans. That was a bad experience... but I was fortunate, FORTUNATE [finger spelled], stayed calm, accepted it (I)(28.45-29.4).*

Now older, Rose has changed her response in situations where she is unable to hear conversation. When younger, she avoided telling people about her hearing loss, fearing a negative reaction, and instead sought to *disguise the fact that I couldn't hear.* Believing hearing loss is now better understood and less stigmatised, she is more open to telling others, removing the need to *bluff my way through:*

> *Well, I don't have to... much really now, I always felt I had to, erm, disguise the fact that I couldn't hear. I bluffed a lot. I made guesses...It's different now (13.12-8)/ I will now tell people, whereas there was a time when I just tried to bluff my way through (67.9-10).*

9.3.3 Tenacity: keeping going

Describing themselves using words such as *strong* and *determined,* some participants understand their ability to withstand challenge as tenacity: they just *keep going.* For example, Matthew explains how he just *gets on with it* and *carries on.* Recalling a period of serious ill health in addition to her deafblindness, Rose asserts that *one way or another, I've coped with that* and in relation to her ability to manage independent cooking, jovially comments that she has *kept up.*

It appears that participants keep going because they believe there to be no alternative or because of a felt sense of obligation. Faye describes independently managing a difficult situation at home, despite her deafblindness, because she *didn't really have that much of a choice;* as she reflects on a possible future without her husband, her felt obligation to keep going is revealed in her observation that *you just have to:*

> *I don't know what I would do, but I think probably, I hope that I would pick myself up, and I would just carry on, I would, you just have to don't you (27.17-9).*

Caroline goes so far as to term a failure to keep going as *immoral*, because *you're letting people down.* It is therefore important for her *to soldier on* and it appears that even during her bleakest moments, she will *just keep going:*

> *Because there isn't anything to look forward to. There's erm, there's, there's deteriorating sight, deteriorating hearing, dementia, infirmity, several types of cancer, stroke, heart attack, erm, being on your own. So, what's there to look forward to? Not a lot. But erm, I just keep going (56.15-22).*

9.4 Accessing and Using Care and Support

As noted in Chapter Seven, being in situations when the support upon which one is dependent is unavailable can engender felt vulnerability among participants (see section 7.2.3.5). This final superordinate theme shows how participants describe making use of care and support, and regard it positively, emphasising the role its presence or absence plays in the vulnerability experience. Participants make use of formal and informal care, aids and equipment, or a combination of these. In developing their reflections, they identify the attributes of valued and effective support, and go on to describe the type of support they desire in the future. Even Caroline, for whom engagement with support can create felt vulnerability, describes a willingness to engage with support in the future, if the approach is as preferred.

9.4.1 Formal and informal support as positive

A range of formal support is used by participants. This includes personal assistants and communicator-guides commissioned and funded by local authorities, and those employed directly via direct payment schemes. Participants also describe making use of training and support provided by rehabilitation officers for visually impaired people and accessing financial support such as *Access to Work* monies and *Motability* schemes to fund access to a vehicle. In addition to individual or one-to-one support, participants engage with communal services, such as deafblind groups and a service offering support to help people manage their hearing aids.

Some care and support is provided informally. This includes that provided by family and friends, and from faith communities. In some instances, support is available very informally. For example, Phillip explains how he receives help from an acquaintance:

> *… always helps me, the lovely… man who comes to the bus stop, he takes me to the shops… And he's very kind to me… he helps me with the bus stop, which is nearby… he takes me out [of the café] when I've finished. When I'm going from the café, he'll take me to the traffic lights and help me across the road (51.28-52.2).*

Participants are supported with a variety of tasks: instrumental activities of daily living, such as housework, shopping, managing medication, and cooking; travelling and mobility; managing correspondence and necessary administrative tasks; accessing and attending educational facilities and programmes; and engaging in leisure and social activities. Matthew describes how support from his parents maintains his capability, as they are able to ensure he is *doing all the correct things that were there to be done.*

Some participants also make use of aids and equipment. This includes specialist equipment: magnifiers, specialist lenses, mobility aids such as symbol canes and long canes, vibrating pagers, liquid level indicators (a devise that alerts a deafblind person when a cup or mug is full), braille output machines and speech software. However, it also includes mainstream equipment and technology, such as mobile telephones, tablet devices (iPads) and use of the Internet and email. Mike explains how he combines equipment and human assistance to mobilise safely, holding on to arm of a sighted-guide, while using his long cane. Phillip similarly combines equipment and human support to access his computer:

> *... all my computer work is done over the telephone, I use headphones connected to the telephone. And I have a computer assistant at the other end of the line (4.30-6).*

Though participants report some limitations with equipment, care and support is highly regarded. Mike explains that *I like being helped* and when a doctor's receptionist offers Phillip help to cross the road outside the surgery, he responds *I'd love some help*. Participants describe the support they receive as *fantastic, wonderful* and *very good.* For Phillip, mobility training from rehabilitation officers is *vital, essential.* The impact the support has on participants' well-being is also important. Celia reports that having communicator-guide support has made *a big difference* and that she now feels *much happier… much better.* Participants also describe support *taking the pressure off* and making things *easier*. It appears that it has a role in helping participants not only complete tasks but also enjoy life. In the following extracts, Matthew explains how assistance from his parents makes walking outdoors more enjoyable, and enables him to do more than just basic cooking, which is the level he can manage alone:

> *I don't have to, they look around for all the, all the hazards and I don't have to look around for all the hazards... I just bounce along like this [uses index finger to indicate someone moving along] quite happily [smiles] (36.36-42).*
>
> *... when I've done, erm, what I call 'high cooking' as it were… I've had, I've always had, erm, assistance (60.21-6).*

9.4.2 Attributes of effective and valued support

Reflecting on their positive experiences of care and support, participants identify particular attributes that they understand as rendering it effective. Data indicate that these attributes appear to negate factors contributing to felt vulnerability: in particular, support is effective when the individual is understood and maintains control.

Understanding is demonstrated by the way others provide care and support. Describing her friend and colleague alerting her to obstacles as she moves around the workplace, being understood appears as important to Faye as the assistance itself:

> *I think gosh she, she's got it [louder voice] she knows what I'm up against (17.19).*

Providing help intuitively, instinctively and discreetly is also valued; in such situations, help does not need to be requested, as both the need for it and the way to provide it is understood. In the following similar extracts, Rose and Faye recall experiencing such assistance, as they find themselves needing support to navigate safely through a public house:

> *Rose: … we went in to, erm, to use, in to a pub to use the ladies… and it was a very bright and sunny like it is today, and immediately that lady… took hold of my hand and walked me through the pub, which was of course in semi-darkness anyway… Erm, but I was so relieved she did that because I wouldn't have been able to see a thing… I couldn't have managed without it, but I didn't have, even have to ask her to do it, she just did, automatically did it (17.2-25).*
>
> *Faye: … as we came out of the pub it was quite busy and err, I kinda tried to negotiate the door and I, we, there was a, a gentleman in our party as well, and I… I sort of bumped into him, and err, one of my friends took my hand [laughs] and sort of led me out [laughs]. Erm and I felt that's really nice, that she just instantly, erm, instinctively, err, led me away and they made sure I sort of got through the car park OK… they looked after me (16.47-17.9).*

Although important, it appears that having an understanding of deafblindness and any associated needs is insufficient. Participants interpret support as effective when they are understood and known as individuals. They describe positive encounters with social workers, health care staff, post officer tellers and those in their faith community when they are known. Phillip contrasts different experiences of having support to manage his hearing aids. Ordinarily the worker he sees knows him and as such, there is *no problem there.* However, he encounters problems, described in Chapter Seven, when she is unavailable and a worker who does not know him is instead present (see section 7.4.1). Rose reports that those who understand her, are those who *actually get close enough to get to know me*. When people do, she describes feeling better supported and respected.

The importance of being known and understood is further illustrated in participants' experiences of positive support as relational. Mike describes having positive relationships with staff at his supported accommodation, and expresses dismay and upset when they have disagreements or when staff move to new employment. The relational element of positively received family support is also apparent, as participants describe engaging in shared hobbies and interests, and having trust in their relatives.

Describing how he interviews for new communicator-guides, Anthony does not comment on their understanding of deafblindness, but rather explains that he asks *about their character* and then does a *trial for a month to see whether we get on.* The importance of a good relationship is key to the effectiveness of the support offered by one of his current communicator-guides, with whom he is *compatible* and *harmonised,* albeit that *sometimes we argue:*

> *[talks to communicator-guide who then leaves the room] You can see, and it's beautiful, you can see the help, you can see the communication there, and the relationship with the communicator-guide. Can you see it? [animated and smiling] It's beautiful. And it's beautiful, it's beautiful. And sometimes we argue, but we have a good relationship. Because she is not only a professional, she's a professional and a human, she is both. We get on very well (I)(11.7-20).*
>
> *... sometimes we argue, but it helps us get closer, we've been working together for 10 years (I)(55.39).*

The relationship Anthony has with his communicator-guide is unlike other support worker- client relationships, in that it appears the support is mutual. Nevertheless, this does not seem problematic for Anthony:

> *So, if some like [communicator-guide] says, 'I'm tired', or maybe if she's got her own problems, sometimes she'll tell me, or she's not happy, then she'll tell me, and I'll say, 'OK, don't worry' and we support each other (56.1-4).*

Support is also deemed effective when it enables the participants to maintain control: when it is provided in a way that does not negate their autonomy. As reported in section 9.2.6, making use of direct payments, and therefore being an employer, supports Anthony and Celia to maintain control. Celia describes how things are also *the same with my daughter*, as together they *decide when to go out* and as such maintain *control through discussion.* The way Phillip and Mike interpret the support they receive as enabling them to maintain control is revealed in the language they use to describe it. Both explain that they receive help *with* or *work with* their personal assistants or support staff rather than being done for, as illustrated in the following extract from Mike's second interview:

> *... sometimes I hoover the floor myself. And, and hoover the kitchen floor. Sometimes I mop the flat, the floor. Sometimes I wash the sink in the bathroom and the staff do the toilet... Then I go shopping and we start get the shopping... they hand it to me and I put it in the trolley. And when I get home, I put it away (31.36-33.12).*

Flexibility also appears to be important, and participants describe valuing support that is available 'as and when'. Anthony explains, that when out socialising, *the guide isn't with me* and that she only comes to him if communication support is required. Phillip and Mike both describe being flexible with their funded hours of support, regularly changing these to enable them to engage in events in which they are interested, as they arise.

9.4.3 Desired future support

In addition to describing their current use of care and support, participants also offer reflections on the type of support they hope for in the future. Those not currently receiving ongoing formal support, describe being *open to it* or giving it consideration. Now getting older and thinking ahead to a time without his parents, Matthew is more than just open to it, asserting that *if I could get the help, I would like someone.* The particular type of support participants describe being interested in varies; some express interest in a guide dog or rehabilitation training, while others describe a desire for one-to-one human assistance. As culturally Deaf people, Anthony and Celia specifically express a desire to avoid mainstream older people's residential care. Nevertheless, data reveal certain attributes of desired future support: that which is relationship based and flexible.

Anthony describes wanting a communicator-guide whom he is *able to relate with,* who *is on the same level as me* and with whom he *can share something.* Although ability to communicate effectively using tactile British Sign Language or deafblind manual are discussed, Anthony does not prioritise these skills. He describes kindness and empathy, arguing that *what's important is that they are human first.* Comparably, in describing his ideal communicator-guide, in some detail, Matthew does not refer to their knowledge of deafblindness or specialist skills, but rather their age, sex and personality. He imagines it being someone who is willing to *stick up for* him and asserts that if *that right person comes… I'm not gonna have a problem:*

> *I don't want someone who's erm, well… Marvin the robot, you know exactly what I mean… if you've got a bouncy personality like I have, and you find someone who's got a, a sort of similar type of personality, you ain't got a problem have you (92.1-93.7).*

Emphasising their preference for care and support based on relationships, in the following extracts, Caroline and Anthony reject what Anthony terms *professional business*, in which defined tasks are completed in exchange for funding, devoid of relational attributes:

> *Anthony: I want to be able to relate to them… for example… an organisation, if they provide me with a guide, I make a list of tasks, so 'take me to the shop' or 'take me to the doctors or the dentist' maybe, and then, that's their job finished. I pay them, and off they go. And that's only business, that's just business. That's the professional business. My relationship, my feelings, maybe I feel lonely (I)(6.14-31).*
>
> *Caroline: … if you have, use a communicator-guide, you want somebody that you can empathise with or who will empathise with you… And that's hard as well. You don't just want somebody off the street, who just says give 'em seven quid an hour and I'll erm walk round with you, you know (23.20-8).*

Participants report that the development of such relationships necessitates *continuity* of support and that they are known. Faye asserts that one needs to *get to know me quite well to know what I'm dealing with*, and Anthony stresses the requirement that he is known as a unique individual, purporting that *they need to understand the depth of my soul.*

Just as it was a valued aspect of currently received support, flexibility also appears to be an important element of desired future support. This is both temporal flexibility and that associated with functional boundaries. Matthew expresses needing support to be available *when necessary* and as illustrated in the following extract, Rose expresses a similar desire:

> *I often think it would be quite nice to have someone, or just some, something you could err, as it were, switch on, that would fill in all the gaps for me when I need them (73.41-44).*

Feeling vulnerable in situations of unplanned change, Matthew maintains a routine at home (see Chapter Seven, section 7.2.3.2). Nevertheless, he explains how he would welcome support that could enable him to move beyond routine and be more spontaneous, taking him where he *might not normally go to, for something a bit different.* Anthony believes realising this desire, which he shares, necessitates communicator-guides to *do something that is outside of their boundaries.* Adhering to a list of defined tasks, which are within set boundaries, means that communicator-guides are not able to address all of Anthony's needs, as he movingly illustrates in the following example:

> *So, for example, if I ask... a guide, 'will you please, I don't know, take me to the pub?' And they say, 'Why?' 'Well maybe I want to find a person to have sex, because I can't have sex here, I can't meet someone for sex here'. Do you understand? So, for example, if I, if you were at home, you can have sex any time you want, but I can't (I)(6.37-47).*

9.5 Conclusion

This chapter presented findings related to participants' interpretation of their experiences of managing and coping. Data reveal that participants are far from passive individuals, but are active in responding to their felt vulnerability and the challenges they face as they age with deafblindness. In the analysis, three superordinate themes were identified. The first two describe how participants adopt a range of practical and psychological strategies, as they develop solutions to the challenges they encounter. Though these vary among participants, data indicate shared approaches, which centre on addressing factors that contribute to their felt vulnerability. The third theme shows the ways in which participants make use of care and support, and the attributes they associate with effective and valued support, both that currently received, and that desired in the future. Comparable to their own solutions, these attributes appear to be focused on negating the impact of elements that contribute to felt vulnerability. Having presented the findings, in the next chapter, I discuss their relationship with other literature, exploring how existing research and theorising further illuminate meaning in the participants' experiences.

CHAPTER TEN - DISCUSSION

10.1 Introduction

The dearth of research on the experience of vulnerability from the perspectives of those who experience it is well documented. The primary aim of this qualitative study was to explore the lived experience of the phenomenon among a particularly marginalised group: older people ageing with deafblindness. As little is known about those ageing with the impairment, with significantly more research attention paid to those with late-life acquired deafblindness, a secondary aim was to explore their experiences of ageing with the condition. 18 in-depth semi-structured interviews elicited rich data, and analysis of the findings was presented in the previous three chapters. In this chapter, I discuss the relationship between these findings and other literature, including, but not limited to that reviewed in Chapter Two. With a particular focus on the experience of vulnerability, this chapter examines how findings of the present study support and extend the existing body of knowledge, thus developing our understanding of the phenomenon. It then similarly considers the findings related to the experience of ageing with deafblindness, before discussing how findings about the way participants cope and manage relate to the very limited literature in the deafblind field that adopts a salutogenesis perspective.

10.2 Deafblindness and Vulnerability

10.2.1 Vulnerability as Layered: Vulnerable About, Vulnerable To, Vulnerable When

Høy et al. (2016) observe, that in the context of older people's health and social care, vulnerability has been understood in 'physical terms', focusing on increasing frailty and bodily functioning. Nevertheless, older participants in Abley and colleagues' (2011) qualitative study describe it as an emotional response to particular situations. In the present study, participants similarly describe their experience in the language of emotion, emphasising the felt nature of vulnerability. These emotions are exclusively negative, but of varying intensity, and include anxiety, worry, fear and panic. Although participants have unique experiences of feeling vulnerable, they all make sense of these as layered, describing not only what they feel vulnerable about and what they feel vulnerable to, but also times when they feel or have felt vulnerable. As observed in Chapter Two, deafblind people are identified by professionals as a vulnerable to a range of adverse outcomes, and yet specific dangers are mentioned infrequently by deafblind people in the existing research literature (see section 2.7.2.4). Comparably, in the present study, telling of experiences when they felt vulnerable dominate participants' interpretations of the phenomenon, rather than the identification of outcomes to which they felt vulnerable. Furthermore, for one participant, Caroline, such outcomes were things she feels 'at risk of' and do not engender felt vulnerability. Although describing times when they felt vulnerable, participants also describe times of safety and security, revealing their experience of the phenomenon as transitory. This echoes findings of other studies, in which both older and disabled individuals reject the notion that feeling vulnerable is an immutable state (Abley et al. 2011, Parley 2010), supporting arguments against the categorisation of particular groups as permanently vulnerable in professional, legal and political spheres.

Although interpreting their experience of vulnerability as layered – vulnerable about, vulnerable to and vulnerable when – before considering these in turn, it is important to note that participants do not understand the layers as discrete, but as interwoven, with instances of one impacting on another. In some instances, participants' own responses to different layers of vulnerability interact, such that one felt vulnerability is diminished, while another is exacerbated. Examples of such experiences appear to provide empirical support for theorising that rejects the notion of autonomy and vulnerability as oppositional concepts (see, for example, Anderson 2014, and Mackenzie 2014), as explored later in this chapter.

In both policy and research, the term vulnerable is principally used as a 'stand alone term (calling someone vulnerable)' rather than 'in its relational sense (where someone is vulnerable to something specific)' (Brown 2011:314). Kohn (2014) argues that identification of the actual threats or problems to which people are vulnerable not only serves to dismantle the association of vulnerability with particular groups, based on their inherent characteristics, but is also essential in ensuring the effectiveness of state intervention in safeguarding people from harm. In the present study, participants identify matters they feel vulnerable about and adverse outcomes to which they feel vulnerable. A general, though not constant, feeling of vulnerability is described by some participants, as similarly reported by LeJeune (2010). Feeling vulnerable about the future is also observed. The potential of further deterioration in hearing and vision is a contributory factor to such experience, as comparably observed in other studies (Miner 1995, LeJeune 2010, Gullacksen et al. 2011). Nevertheless, the present study shows how for those ageing with deafblindness, earlier experiences, including those occurring in childhood, and awareness of the negative experiences of others, can also contribute to felt vulnerability in a general sense.

Similar to older people with late life acquired deafblindness (Pavey et al. 2009, Sense 2012, Viljanen et al. 2012), participants in the present study identify physical harms or injury associated with falling and accidents, social isolation, and being a victim of crime, as outcomes to which they feel vulnerable, or in Caroline's case, at risk. Some participants also refer to fears of being taken advantage of or exploited, an experience conceptually associated with vulnerability (see, for example, Goodin 1985, and Wood 1995). However, participants make little to no reference to feeling vulnerable to abuse, particularly in the context of care and support. Indeed, Caroline explicitly refutes this, stating that she does not think she would *be vulnerable to any kind of abuse from a communicator-guide.* This supports the finding in the literature review that the particular vulnerability of deafblind people to such abuse concerns deafblind children and congenitally deafblind people with additional needs, rather than the deafblind population as a whole.

Notwithstanding their identification of the matters outlined above, it is the discussions about times when they felt or feel vulnerable that dominate participants' interpretation of their experiences. Demonstrating the situational as a source of vulnerability, as contained in Mackenzie, Rogers and Dodds' (2014b) taxonomy (see Chapter One, section 1.4.1), times when participants felt vulnerable are situation and setting specific, and both fleeting moments and extended periods are reported. The situations and settings creating vulnerability are individual to each participant, and include actions such as crossing roads, being in hospitals and unknown places, and the actions or reactions of other people. Nonetheless, participants describe shared elements of the vulnerability experience, and these both correspond with findings of other studies and illustrate the non-distinct nature of the three sources of vulnerability -inherent, situational and pathogenic - in Mackenzie and colleagues' taxonomy.

Arndt and Parker (2016) maintain that it is widely reported that deafblind people have difficulties socialising. Such difficulties can contribute to a reduced sense of well-being, particularly for older deafblind people (Erber and Scherer 1999). The present study shows how social settings can also engender felt vulnerability. Participants describe how difficulties initiating and engaging in conversations owing to their deafblindness produce fears of misunderstanding, being left alone or appearing foolish in such settings: the situational amplifies the inherent source of vulnerability. Feelings of embarrassment and anxiety in social settings are similarly reported by older deafblind people in other studies, including those ageing with the impairment (Heine and Browning 2004, Göransson 2008, Gullacksen et al. 2011). For those using tactile communication, the present study reveals that other people's inability or unwillingness to use such communication methods can also contribute to the vulnerability felt. Arguably, this reflects pathogenic vulnerability at an interpersonal level, albeit that such inability or unwillingness is not necessarily deliberate or malevolent.

Feeling vulnerable when sensing one is losing control or being controlled by others is observed in studies involving both non-deafblind older people (Abley et al. 2011, Høy et al. 2016) and deafblind adults (Danermark and Möller 2008, Kyle and Barnett 2012), and was similarly reported in the present study. Participants also report feeling vulnerable in situations in which they 'lack the full picture' owing to the absence of accessible information, including that about their current environment. Perhaps understandably therefore, all participants report feeling particularly vulnerable when in unknown places or situations, with some highlighting the impact of unrequested or unplanned changes in their routines. This mirrors findings of other studies (Danermark and Möller 2008) and supports Kyle and Barnett's (2012) argument that in such situations, deafblind people enter the 'domain of vulnerability'. By highlighting that lack of information is not only associated with their deafblindness, but with others' failure to provide accessible information, participants in the present study illustrate the contribution of situational, inherent and pathogenic factors in such settings.

Within their taxonomy, Mackenzie et al. (2014a) contend that inherent sources of vulnerability can vary dependent on an individual's resilience or capacity to cope. Similarly, as noted in Chapter One, Schröder-Butterfill and Marianti (2006) include coping capacity within their framework for understanding vulnerabilities in old age (see section 1.4.1.). Providing empirical support for such inclusion in our understanding of the phenomenon as experienced by those ageing with deafblindness, participants describe feeling vulnerable when they sense they are unable to withstand challenge or threat. For example, Anthony explains that feeling unable to cope with the experience of isolation, rather than isolation itself, creates his felt vulnerability.

It appears that one's capacity to cope is not solely associated with inherent characteristics, such as one's impairment or personality. Participants describe various tangible and intangible factors that support their coping capacity, and as such diminish feelings of vulnerability. Paid employment, for example, provides Faye with multiple benefits, including social interaction, self-worth and the opportunity to present herself as capable. The loss of such benefits upon retirement is particularly significant in Caroline's experience of vulnerability and her ability to cope. While there is a paucity of research on the employment of older deafblind people, McDonnall and LeJeune (2008) report that many either work or have a desire to work. For those with Usher syndrome Type II (like Faye and Caroline), Ehn et al. (2019) observe that those in paid employment had better health compared to those out of work. However, deafblind people are reported as more likely to be unemployed than those with other impairments (World Federation of the Deafblind 2018) and as members of two stigmatised and marginalised groups (Phillips et al. 2010), older deafblind people may experience high levels of exclusion from the labour market. McDonnall and LeJeune's (2008) study revealed that of those older people not in employment, hearing-sighted people had chosen this status, while deafblind older people had not. Furthermore, despite a number of countries raising their retirement age (Dordoni and Argentero 2015) and many older non-sensory impaired employees reporting that they envisage a continued working life beyond this age (Brown 2003), early retirement following the onset of deafblindness is common (World Federation of the Deafblind 2018). Participants in LeJeune's (2010) research felt that acquiring a second sensory impairment had resulted in the early termination of their employment, while participants in Arndt and Parker's (2016) study felt they were 'forced' to leave work. In the present study, this was an experience described by Phillip and feared by Faye.

A lack of available or effective support for deafblind adults is reported across the literature (Kyle and Barnett 2012, Prain et al. 2012, Simcock and Manthorpe 2014, Arndt and Parker 2016) and is associated with reduced quality of life (Ehn et al. 2019, Simcock and Wittich 2019). Data from the present study resonate with such findings, as several participants describe situations when support upon which they are dependent was not available. Furthermore, findings of the present study illustrate how the unavailability of support is not only associated with diminished quality of life, but also felt vulnerability. Participants explain feeling vulnerable when required support is either unavailable or withdrawn; in Faye's words, in situations when the *crutch is taken away.* This includes not only formal and informal human assistance, but also adaptations and mainstream services such as temporary bus stops, the removal of which has a disproportionate impact on Phillip compared to his fellow hearing-sighted travellers.

Westwood and Carey (2018) contend that health and social care services are ill-equipped to meet the needs of disabled people in later life, noting that disability organisations are not always able to respond to 'ageing issues', while services for older people often fail to respond to disability related matters. They also maintain that health and social care systems are often designed around 'individual diseases rather than conditions involving multimodality' (*ibid.:234)*. As reported in Chapter Two, those ageing with deafblindness similarly report mainstream older people's services as unable to meet their needs (Göransson 2008, Spring et al. 2012, Stoffel 2012) and in the present study, participants interpret such inability as one reason for the unavailability of support, in addition to matters relating to role boundaries and, for those using British Sign Language expressively, requests for support being misunderstood.

Hersh (2013a) reports that the UK has an insufficient number of qualified communicator-guides, and difficulties finding appropriately skilled staff are described by participants. Nonetheless, participants also interpret the unavailability of support as due to inadequate public funding, or the gatekeeping actions of local authorities or government departments. Participants report that it is not because they are dependent upon support that they feel vulnerable, but that the support is not made available to them. Drawing on the theorising of Scully (2014), the source of their vulnerability in such situations is arguably pathogenic. Adopting a relational perspective on autonomy, Scully (2014) maintains that dependence upon others is a reality of all human experience, and the fact that disabled people may need assistance with tasks that the majority do not, does not in itself create vulnerability or negate their autonomy. Nevertheless, to maintain their autonomy, 'the contribution by another person or service [must] actually be made – it is a vulnerability' (*ibid.*:213). She goes on to highlight a distinction between the dependencies of the non-disabled majority, giving the example of good roads facilitating one's commute to work, and those of disabled people, giving the example of braille signage – in the present study, specialist communicator-guide support. The dependencies of the majority are met unquestioningly (if they are in fact seen as dependencies at all), while those of disabled people are perceived as an indicator of their increased vulnerability, and may not be met; this, Scully argues, is political choice (*ibid.*). In perceiving participants' dependence on communicator-guide support as evidence of their increased vulnerability as disabled people, and deeming it, in Scully's words 'a non-permitted dependency', a further political and economic decision is then made in relation to whether it is met. There is reported evidence that deafblind people's needs, are sometimes unmet, despite legal entitlement (Simcock and Manthorpe 2014, Waheed 2016, Simcock 2017b): their vulnerability is the result of a socio-political injustice, and as such, pathogenic.

Notwithstanding the above, Caroline's dichotomous interpretation of the use of support as engendering her felt vulnerability is similarly pathogenic: a response intended to ameliorate vulnerability ironically generates new ones (Mackenzie et al. 2014a). As a disabled person, Gill (2006:191) reflects on both her own and other disabled people's experience of 'being harmed by people who think they know what we need and trying to help'. Kiekopf (2007) posits that the interactions and relationships between deafblind people and health and social care practitioners may impact on levels of vulnerability. Just as deafblind participants in existing qualitative inquiry describe feeling vulnerable to overprotection (LeJeune 2010, Hersh 2013a), Caroline explains how her use of support creates vulnerability, as she begins to question her own abilities and becomes increasing aware of her impairment.

10.2.2 Vulnerability as Dependent on the Responses of Others

In their study of deafblind students' participation in education, Möller and Danermark (2007) observe that whether others were considerate or not was important in the participants' experiences. Other people's inconsiderate and hurtful attitudes were so significant to those adults with acquired deafblindness participating in Schneider's (2006) doctoral study, that they were deemed more problematic than the impairment itself, and the world considered 'hostile'. In the present study, only two participants comparably describe encountering what they perceive as threatening, intimidating or otherwise hostile behaviour from others, and this engenders felt vulnerability. Nevertheless, all participants explain how their experiences of vulnerability can be dependent on the responses or perceptions of others, irrespective of whether these are intentionally antagonistic. As presented in Chapter Seven, two responses in particular were identified as outcomes to which, or situations when, participants felt vulnerable: being or feeling misunderstood and being perceived as incapable.

Alley and Keeler (2009:3) contend that because of its complexity, deafblindness is an 'unrecognised disability'. Lack of recognition of the impairment contributes to misunderstanding of the condition (Simcock and Wittich 2019), and yet this is maintained at an international level in both law and policy. For example, although the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD) acknowledges deafblind people's unique needs (Jaiswal et al. 2018), having monitored implementation of the CRDP for a decade, the World Federation of the Deafblind (2018) report that, from the data available, only 37% of countries (n=50) officially recognise deafblindness as a distinct disability. The World Report on Disability (World Health Organization 2011) makes only seven references to deafblind people, ten times less than references to those with single sensory loss. Simcock and Wittich (2019) argue that a particular group that go unrecognised is older deafblind people. In the CRDP, the specific mention of deafblindness in *Article 24* relates only to deafblind children, and while *General Comment Number 2 on Article 9* makes two references to deafblind people, the second specifically concerns deafblind students, in the context of the school curriculum.

At an individual and interpersonal level, Sauerburger (1993) describes working with deafblind people who are very surprised to learn that the public are unclear about deafblindness and deafblind people's needs. Contrastingly, participants in the present study, describe being, feeling and expecting to be misunderstood: a phenomenon Gill (2006:187) terms the 'alien factor', and one she considers significant in the construction of disabled people's vulnerability. For some participants, feeling misunderstood begins in childhood, but is experienced throughout their lives. It is not only the condition itself that is misunderstood, but also the extent of their impairment, its nature and impact, their behaviour, and their linguistic and communicative methods and needs. Just as participants in other European studies report their needs being misunderstood in health and social care settings (Gaspar et al. 2017, Ehn et al. 2019, Göransson 2008), participants in the current study describe feeling misunderstood not only by family and members of the public, but also professionals in such settings. While such findings support the call for increased awareness among both the public and professionals (Evans 2017b), better understanding of the impairment alone appears insufficient. As noted in Chapter Nine, participants in this study interpret being known and understood as a unique individual as an important element of effective and valued support (see section 9.4.2). In desiring support based on positive relationships, being known and understood in this way appear to be prioritised over support workers' knowledge of deafblindness.

In making sense of their experience of being or feeling misunderstood, participants seek to explain its occurrence. They do not refer to lack of recognition at a policy or legal level, perhaps reflecting the fact that the impairment is recognised in English law (See Chapter One, section 1.3.1). Instead, they identify factors such as ignorance or unconscious incompetence at an individual level, comparatively low prevalence rates such that it is outside most practitioners' experience, and the late diagnosis of their condition, a phenomenon similarly reported in other UK based studies, particularly those involving adults with Usher syndrome (see, for example, Ellis and Hodges 2013a, and Evans 2017b).

Participants also refer to the invisible or hidden nature of deafblindness as a contributory factor to misunderstanding, as similarly reported in qualitative inquiries into the experience of adults with other invisible impairments, such as neurological disorders, chronic pain, haemorrhagic stroke and mental illness (Stone 2005, Lingsom 2008, Mullins and Preyde 2013). Common to others with invisible impairments, and those deafblind people acquiring visual impairment in later life (Hersh 2013b), some participants describe an associated need to tell others, but a fear that doing so may be met with disbelief. Within the literature on invisible impairments are descriptions of people attempting to present as non-disabled, a term Goffman (1963), in his work on stigma, terms as 'passing'. While attempts at disguising their deafblindness, particularly their hearing impairment, are observed among participants in the present study, presentation of oneself as more impaired, in order to avoid misunderstanding and disbelief, is also reported.

Associated with 'a distrust of mere spoken claims to disability', Lingsom (2008:9) observes, participants making use visual markers, such as white canes or other mobility aids, as a way of telling people, as do Mullins and Preyde (2013) and Ehn et al. (2019). Phillip engages in similar behaviour, using both his red and white cane and braille watch, in order to tell others. Nevertheless, participants also describe declining to use such aids. Some studies report that fears of stigma and difficulties accepting one's deafblindness are key reasons for such refusal (Ellis and Hodges 2013a, Hersh 2013b). However, the present study highlights how fears that the meaning of such aids will be misunderstood, therefore rendering the equipment ineffective or provoking unhelpful responses, are also contributory factors.

All participants describe feeling vulnerable when and feeling vulnerable to people perceiving them as incapable or incompetent, a finding echoed across both the deafblind literature (Stiefel 1991, Smith 1993, Miner 1997, Deafblind UK 2007, Pollington 2008, LeJeune 2010, Bodsworth et al. 2011) and wider disability literature (Shotton and Seedhouse 1998, Gill 2006). For some participants, such perception was experienced in childhood, as they encounter the low expectations of family and education professionals, compared to their hearing-sighted siblings and peers. Nevertheless, it is reported as experienced throughout their lives, increasing as they get older, and for some, occurs in the context of existing low self-esteem. The perception of incapability is experienced when participants feel patronised, mocked or laughed at, but also when they receive offers of well-intentioned but unnecessary assistance or encounter others' disbelief in their ability to do things for themselves. In responding to such experience, participants seek out and value recognition of their capability. Indeed, for Phillip, such recognition is central to his ability to cope with both his vulnerability and deafblindness.

Scully's (2014) notion of 'ascribed global vulnerabilities' assists our understanding of how some participants interpret the origins of such perceptions. This concept refers to the extrapolation of genuine vulnerability in one element of a disabled person's life to its entirety (*ibid.*). For some participants in the present study, this appears to operate at both the interpersonal and policy levels. For example, in relation to the former, Mike explains how support workers question his ability to manage his money, interpreted as based on his need for support with other domestic tasks. Illustrating the phenomenon at a policy level, Anthony understands an airline company's policy of not allowing disabled people to fly alone, as based on a blanket assumption that they are incapable of managing their own safety. Enhancing the impact of the ascription of global vulnerability in this instance, it appears deafblind people are perceived as an homogenous group. Seeing himself as capable of managing his safety when appropriate communication support is provided, Anthony laments the lack of 'criteria' to differentiate between deafblind individuals. As Smith (1993) argues, the homogenisation of the deafblind population, which includes congenitally deafblind children with additional intellectual impairment (whom both the practice and research communities have a longer history of focusing upon), risks increasing the vulnerability of the 'just' deafblind.

Irrespective of the nature or cause of perceptions of incapability, findings in the present study highlight its particular significance in the participants' experiences of vulnerability. Such is the fear of being seen in this way, some participants describe avoiding situations in which it may occur, albeit that such situations may be desired. This has a somewhat iatrogenic affect: as the vulnerability to the perception of incapability is diminished, vulnerabilities associated with isolation and loneliness are realised and intensified. In Caroline's case, allowing herself to be vulnerable to the perception of incapability by engaging in the social interaction that she so desires, might not only reduce her isolation, but also provide an opportunity to express her competence and be recognised by others as such. This appears to illustrate the position of Anderson (2014), who argues against the presentation of vulnerability and autonomy as oppositional, and posits that the 'realisation of autonomy is ineluctably bound up with certain forms of vulnerability' (*ibid.135*). In Brené Brown's words, 'the courage to be vulnerable' has the potential to be transformative (Brown 2013:2).

10.2.3 The Vulnerability of the Researcher

Although reflexive researchers must consider their impact on the research (Carolan 2003), how undertaking the study impacted upon them should also be explored (Gair 2002, Pillow 2003, Gilgun 2008, Dickson-Swift et al. 2009). Fears that acknowledgement of the emotional impact of fieldwork highlights subjectivity, and thus challenges the trustworthiness of research, result in such effects being unexplored in methods literature (Liamputtong 2007, Dickson-Swift et al. 2009). Nevertheless, qualitative researchers do describe the ways in which their fieldwork affected them (Liamputtong 2007); Smith (2006:209) contends that doing so results in 'more realistic qualitative research'. As this study explored the experience of vulnerability, it appears particularly apt therefore to reveal my own vulnerabilities throughout its completion.

All those involved in qualitative research on sensitive topics can be affected, and such study has the potential to be transformative, challenging, painful and risky for the researcher (Finlay 2002, Dickson-Swift et al. 2007). Concerns about the personal safety of researchers and both physical dangers and emotional demands have all been noted (Connolly 2003, Dickson-Swift et al. 2006, Liamputtong 2007, Lillrank 2012). The latter includes emotional vulnerability (Dickson-Swift et al. 2007), emotional exhaustion (Dickson-Swift et al. 2006, 2009), and vicarious trauma or 'compathy' (Liamputtong 2007, Gilgun 2008, Lillrank 2012). Liamputtong (2007) acknowledges that not all qualitative researchers are emotionally affected by their work, but suggests that the impact can be underestimated. I was not immune from physical, and as noted in section 3.4.4, emotional demands during the study reported in this thesis.

Dickson-Swift et al. (2007) maintain that data collection in qualitative research is intense, and like others (see, for example, Dickson-Swift et al. 2009) I found undertaking the interviews physically tiring. This was associated with travelling and the communicative challenges associated with deafblindness, but for the initial interviews, anxiety and difficulties completing qualitative interviews as a novice researcher also had a role. Some of these difficulties related to the move from interviewing as professional social worker, with which I was familiar, to interviewing as researcher; this is an experience shared by other social work researchers (see, for example, Lillrank 2002). As such, as Johnson and Rowlands (2012:106) report, for the novice researcher, 'the learning curve is steep' at this stage of a study; my learning from the pilot interview is described in section 4.2.4.

Failure to manage boundaries in the researcher-participant relationship can engender an adverse emotional effect (Dickson-Swift et al. 2006). I have developed an ability to maintain appropriate boundaries through professional qualification and experience. Nonetheless, owing to the level of rapport, and indeed intimacy required for successful in-depth phenomenological interviews, managing boundaries is complex, even for those with a professional health care or social work background (Carolan 2003, Dickson-Swift et al. 2006, 2009). Demonstrating emotion during interviews has been described as both necessary yet problematic (Dickson-Swift et al. 2007, 2009, Lillrank 2012). However, the first of my boundary associated vulnerabilities echoes the experience of social worker and researcher Kanuha (2000:443), who describes being 'both troubled and honoured' upon receiving a participant's invitation to dinner. I was similarly affected by a participant's kind invitation to lunch, reflecting my professional norms in relationships outside of family, friendships or employment. The situation was illustrative of the problems that arise when perspectives on boundaries differ between researcher and participant (Corbin and Morse 2003). Although initially uncomfortable, I accepted the invitation, and the opportunity to engage in informal conversation prior to the interview was helpful in developing necessary rapport. The second of my vulnerabilities associated with boundaries is that described in section 3.4.7: leaving the field and having ongoing concern for participants, phenomena observed in the qualitative methods literature (Gair 2002, Dickson-Swift et al. 2006, Liamputtong 2007). Though in part this reflected the time spent with participants, intimate nature of in-depth interviewing, and topic under investigation, it was amplified by my dual identity as social worker and researcher.

Goldspink and Engward (2019:298) assert that data analysis in IPA research is 'intrinsically connected to the complex and dynamic life world of the researcher'. This stage of study can also have an emotional effect on the researcher (Finlay 2002, Dickson-Swift et al. 2007), as I encountered. Transcribing and analysing the interviews was an emotional experience, as others have noted (Gair 2002, Dickson-Swift et al. 2007). As analysis commenced, I experienced the discomfort among novice IPA researchers described by Biggerstaff and Thompson (2008), as I tentatively offered interpretations of meaning. The reflection of Vicary et al. (2017:556) that in IPA research one must 'stop thinking about the process of analysis and get on with the doing of it' was helpful. Nevertheless, my concern to 'get it right' reflected my sense of responsibility to represent participants' voices authentically. This sense of responsibility was heightened because of the extent to which participants so willingly shared their personal experiences, something common in qualitative study (Dickson-Swift et al. 2007). As analysis continued, I experienced a variety of emotions, including sadness, inspiration and anger. Emotions emerged as I remembered each participant, but also, as observed by Goldspink and Engward (2019), as I confronted experiences in my own life: experiences of being 'othered', of being excluded and of feeling vulnerable. An especially moving moment was the realisation that participants had substantially altered my thinking in relation to the experience of being misunderstood. I have often felt frustrated at the lack of understanding of deafblindness among both the public and health and social care professionals. As participants described their experiences of being misunderstood, interpreting the reasons for it (see section 7.4.2), my frustration dissipated and my perspective became more sympathetic. Exploring my vulnerabilities as researcher, thus reveals the ways in which the study has been personally challenging and emotional, yet also transformative.

10.3 Ageing with Deafblindness

Deafblind people are 'one of the most heterogeneous, low-incidence disability groups' (Arndt and Parker 2016:369). As demonstrated in the first two chapters of this thesis, older people ageing with the impairment appear to be a particularly hidden group, within both research and policy: they are a minority within a minority. Simcock and Wittich (2019) argue that this knowledge gap contributes to their exclusion from social welfare policy and disability development programmes, and diminishes the potential for them to benefit from international human rights provision. The present study shows how participants make sense of the experience of ageing with the impairment, therefore offering important new insights in the field.

Securing recognition of deafblindness as a third, discrete sensory impairment has been central to the campaigning activities of both international and national organisations of and for deafblind people (World Federation of the Deafblind 2018, Simcock and Wittich 2019). As observed by Arndt and Parker (2016:372), those working and researching in the field are 'quick to point out that deafblindness is a unique disability' and not 'merely the sum of vision and hearing loss'. Nevertheless, findings of the present study show how participants frequently describe their impairments separately, albeit for some, they are beginning to see them together as they get older. Such separation appears to be associated with certain factors: each impairment having a different trajectory of deterioration (or improvement); the timing and order of onset; and experiencing one as more evident than the other, dependent on time, situation, setting and context. It appears such separation, combined with ageing, contributes to participants' sense of multiple identities. Participants' identity is not static; throughout their interviews, they refer to themselves in different ways. They describe former single sensory impaired selves, yet sometimes maintain single sensory identities: I am blind, I am Deaf. For those with Usher syndrome Type I, this in part reflects their cultural affiliation to the Deaf community. Legal processes seem to have function here, with some participants identifying as *registered* blind. Having residual vision, particularly later in life, also appears to contribute to a sense of multiple identities.

Grue (2016) claims that the way in which people identify with specific types of impairment is not fully understood. There is a particular paucity of research on deafblind people's identity, but existing studies suggest that a contributing factor to it is whether the individual's deafblindness is congenital or acquired (Arndt 2010a, Hersh 2013b). This distinction between congenital and acquired deafblindness, described in Chapter One (see section 1.2.2), is long-standing in research, policy and practice (Dalby et al. 2009, Dammeyer 2014). Although such distinction has been described as overly simplistic (Wittich and Simcock 2019) and artificial (Moller 2003, Clark 2014), it is the ageing with deafblindness population, which includes people across this divide, that specifically highlights its inadequacy. For example, the population comprises of those ageing with congenital conditions, such as congenital rubella syndrome, but also those for whom one impairment is congenital and one acquired in childhood or early adulthood, and those for whom both impairments are acquired in childhood or early adulthood (Wittich and Simcock 2019). It also includes those with a congenital condition that results in acquired deafblindness, such as Usher syndrome. The group of participants in the present study, albeit small in number, illustrate this complexity: one had congenital deafblindness; one had congenital deafblindness with subsequent trauma resulting in further sight loss; two had congenital profound deafness and acquired sight loss in childhood; three had congenital hearing impairment and acquired sight loss in early adulthood; and one acquired both visual and hearing impairment in early adulthood. Grue (2016) argues that disabled people principally identify with discrete impairment categories, rather than the 'single category that is anything like disability'. Those ageing with deafblindness do not 'fit' clearly in existing categories within the deafblind population, formally recognised in research and policy. In addition to challenging the adequacy of the distinction, this may also therefore contribute to participants' sense of multiple and changing identity. In her UK based study involving ten people across different sub-categories of the deafblind population, Barnett (2002) similarly reports that participants did not define themselves as deafblind. In observing no shared language, behaviour or identity, she concludes that there is no deafblind culture, but rather shared deafblind experience. Such findings trouble Evans' (2017b) recommendation that deafblind people are supported by encouraging their engagement with deafblind culture, but are supported by the findings of present study: participants have experiences of deafblindness, rather than 'be deafblind'.

Central to the participants' experiences of deafblindness are difficulties because of the inability for one impairment to compensate for the other, which is reported across the literature concerning all sub-groups of the deafblind population (see Chapter One, section 1.2.1). Though such difficulties are recognised irrespective of the extent of each impairment (Spring et al. 2012), Hersh (2013b) contends that attention has focused on the interaction of the impairments themselves, rather than the impact of wider social and structural concerns. Nevertheless, findings in the present study show how difficulties compensating transcend the inability of one sense to offset impairment in the other but are multi-faceted. Situational and setting specific elements are contributory to such difficulties. This includes environmental factors, the actions or inactions of other people, and the design of equipment. Furthermore, such factors, combined with deafblindess, impact on participants' otherwise ability to compensate for the dual impairment, by drawing upon others senses such as touch or ordinarily effective strategies. For example, Mike is unable to make use of touch in certain retail settings, and Celia's use of written expression to compensate for others' inability to understand British Sign Language is compromised not only by her vision but poor lighting conditions, associated with the setting and time of day. Arndt and Parker (2016) argue that deafblind people's communication needs must be understood as 'affected by both the environment and the individual'; findings in the current study support such argument, but for those ageing with deafblindness this may also include functions beyond communication.

Findings presented in Chapter Eight challenge any notion that those with life-long conditions find them easier to manage than do those ageing into impairment. Participants describe ongoing and increasing challenges, as they get older, which can render daily life stressful and wearing. Faye interprets the experience as the difficulties *closing in,* a phrase similarly used by others ageing with the impairment, as noted in Chapter Two (see section 2.6.2.4). Getting older and deafblindness are observed to interact in a way that further complicates life for the participants: this includes having difficulty understanding the ageing process itself, owing to life long problems accessing information. There are some reports in the literature of those ageing with deafblindness 'getting used to' the impairment and any associated challenges (see Chapter Two, section 2.6.2.3) and similar experiences are described by some participants in the current study. Nevertheless, findings highlight that such 'getting used to' may be limited to the practicalities of managing challenges and not their emotional impact.

Experiences of multiple changes are commonly reported among people ageing with deafblindness (Oleson and Jansbøl 2005, LeJeune 2010, Gullacksen et al. 2011, Spring et al. 2012). Though similarly described by participants in the present study, as a significant aspect of their lives, this research shows how some changes are understood as indicative that a benchmark has been reached: these are certain points marked by new experience or increased awareness of impairment. Comparable to findings in Arndt and Parker's (2016) study, changes unrelated to deafblindness, such as moving home, and those related to the effects of the impairment were described. Nonetheless, it was changes in hearing and vision that dominated participants' discussions, providing further challenge, in addition to that already made in Chapter Two, to the description of sensory impairments as 'stable' conditions. Akin to other study findings (Yoken 1979, Ellis and Hodges 2013a), changes reported include both deterioration and improvement. Deterioration in vision was largely associated with the progressive nature of retinitis pigmentosa present in those with Usher syndrome. However, change was also described by those with congenital rubella syndrome, Matthew and Rose, and by participants older than those involved in previous studies, highlighting its interminable nature.

In response to such changes, participants' describe the need to make repeated adjustments: for Phillip, making such adjustments appear central to his interpretation of getting older. Comparable experience is reported in existing literature (Simcock 2017a), though participants' in the current study show how adjustments may take place in both a planned or impromptu manner. In the context of communication, Hersh (2013a) observes that adjustments are not only required of the deafblind person, but also their interlocutors. It appears that mutual adjustment may also be necessary in other contexts, such as social interaction, employment, and mobility. The ongoing and repeated nature of the need to adjust can be stressful and wearing for the person ageing with deafblindness. As shown in the present study, this nature may also contribute to the failure of others to adapt: it is associated with their forgetting to do so, rather than their reluctance.

10.4 Managing and Coping

Pruchno et al. (2015) suggest that understandings of successful ageing be reconsidered. Rejecting the notion of the avoidance of ill-health or impairment as indicative of success, they present it instead as 'a pattern of resilient trajectories in response to adversity over the course of a person's life' (*ibid.*:204). This, they argue, acknowledges that those ageing with impairments can and do age successfully. Westwood and Carey

(2018) argue that research involving those ageing with impairments can actually enhance our understanding of resilience and positive adaptation. Furthermore, a focus on resilience, rather than difficulties and problems, challenges negative perceptions of disabled lives as inherently vulnerable lives (Björnsdóttir and Svensdóttir 2008) and older people as a societal burden (Lloyd and Sullivan 2018). Nonetheless, as observed in Chapter Two, there is a paucity of research in the field of deafblindness adopting such a focus, and therefore, findings in Chapter Nine of this thesis provide an important contribution.

Combining findings from the research presented in this thesis with those emerging from two recent qualitative studies, one from the United States (USA) (Arndt and Parker 2016) and one from Sweden (Ehn et al. 2019), helps to build a picture of the many ways in which deafblind adults actively, and often creatively, respond to the challenges they encounter. Participants in each study represent diverse groups of deafblind people. Those involved in Arndt and Parker's (2016) study (n=10) were aged between 26 and 62 years of age, and were deafblind because of Usher syndrome Type II, Type III, Ichthyosis or a condition unspecified. Those in the Ehn et al. (2019) study (n=14) were aged between 20-64 years of age and were all deafblind because of Usher syndrome Type II. The participants in the current study are described in Chapter Six. Despite this diversity, comparable findings are evident, and show how deafblind adults use practical and psychological strategies to manage the difficulties they encounter.

Participants in the current study tell of the ways in which they maintain control in their lives, and 'being at the helm' is the term used by Ehn et al. (2019) to understand the main way in which their participants manage difficulties in their lives. Similar to the present study, Ehn and colleagues also observe the role that telling and educating others about their impairment has in the coping strategies of participants, and in both studies, this is described as essential, yet ongoing and not always effective. On occasions, in both studies, participants move beyond just telling and educating other people, and actively challenging them; the need to be assertive and stand up for oneself is described across all three studies.

Telling of their achievements, skills and talents, participants in the present study also explain how they demonstrate their capability to others in several ways. Such demonstration was similarly observed by Ehn et al. (2019), and just as participants in the current study often reveal their competence through their support of others, Arndt and Parker (2016) report on the role assisting other people plays in their participants' sense of resilience. Nevertheless, participants across the three studies not only care for others, but also for themselves. This includes self-care strategies, such as engagement in hobbies, escapism, having a coffee, and the use of humour; the latter is also observed by Högner (2016) in her study involving those with Usher syndrome. It also involves maintaining social and emotional connections with other people, and psychological strategies such as acceptance, positive thinking and having a sense of tenacity. Although individual to their particular circumstances, participants in all three studies also describe drawing on reserves available to them: this includes wisdom gained from their parents, their memories, and residual hearing and vision. Cullati et al. (2018) argue that the use of reserves has an important role in diminishing vulnerability in later life, but distinguish them from resources. Reserves are conceptualised as those things for future rather than immediate use. Rose's earlier learning of deafblind manual, illustrates the role of reserves conceptualised as such. Deafblind manual is not a communication method she needs to use now, but having learnt it already, she can *bring it into action* when needed. Finally, use of formal and informal support also has a role in the lives of participants, observed across the three studies. This includes engagement with formal, state funded and organised services, use of various aids and equipment, and also support form family, friends and neighbours.

Ehn et al. (2019) argue that their findings problematise the perception of deafblind people as vulnerable. What the current study shows is that the ways in which participants manage their difficulties resonate with the elements they identify as generating their felt vulnerability: being and feeling misunderstood; feeling unable to withstand; isolation; lacking the full picture; losing control; and being perceived as incapable. The type of care and support they both value and desire is similarly observed to address the elements they interpret as contributing to their experiences of vulnerability.

10.5 Conclusion

There is little qualitative inquiry exploring the lives of deafblind people, particularly those ageing with the condition, and a dearth of research on the experience of vulnerability from the perspectives of those who experience it. In this final chapter, I explored the relationship between the findings of the present study and existing literature, to show how they support and extend our understanding of these phenomena. This discussion demonstrates how the findings support arguments against the categorisation of particular groups, including deafblind people, as permanently vulnerable. Experiences of vulnerability are time-limited, and situation and setting specific, and reflect Mackenzie and colleagues' taxonomy of vulnerability: inherent, situational and pathogenic. Situational and pathogenic sources include the responses of other people at an interpersonal level, and the experience of being misunderstood or perceived as incapable is observed across studies of both deafblind people and other disability groups.

Those ageing with deafblindness specifically highlight the inadequacy of the long-standing congenital-acquired divide in the research, policy and practice communities. Their spanning of this divide may contribute to their sense of multiple identities, and the findings of this study support those of others, that deafblindness is more an experience than an identity. While those ageing with the impairment may experience vulnerability, challenge, and ongoing difficulties, study findings, particularly when seen alongside the limited number of published studies adopting a salutogenesis perspective, reveal the active and often creative ways in which they manage their lives. Although clear similarities in findings are evident, the present study shows that the ways in which participants manage their difficulties respond to the very elements they identify as generating their felt vulnerability.

CHAPTER 11- CONCLUSION

11.1 Conclusion

Deafblindness is a complex impairment and research into the condition is in its infancy. There is a particular dearth of qualitative research into the lived experiences of deafblind people and there are consequent calls for such studies. Just as the provenance of organisations of and for deafblind people is found in shared concern about deafblind children, the research community similarly had an initial focus on deafblind children and their educational and rehabilitation needs. Research on other deafblind groups has now emerged, including that considering the needs and experiences of older deafblind people. Nevertheless, this has tended to focus on older people with late-life acquired deafblindness, and comparable to other groups ageing with impairment, little is known about those ageing with the condition.

Little is also known about the lived experience of vulnerability. Research on the concept has principally concentrated on theoretical debate or policy analysis. However, studies exploring experiences and understandings of the phenomenon, published in the health and social care literature, reveal differences between the perspectives of professionals and the perspectives of those with whom they work. The tendency to describe vulnerability as related to the presence of certain inherent characteristics, including old age and disability, is observed in English law, policy and professional practice. More recently, legislation and common law doctrine appear to have acknowledged more nuanced understandings of the concept. This includes recognition of its situational origins. Nonetheless, some argue that an intrinsic connection between an individual's need for care and support, associated with impairment, and their demarcation as 'vulnerable', remains evident in both law and practice. Irrespective of definitional complexity, as a concept associated with need, risk and the need for protection, an understanding of the phenomenon and its meaning in the lives of people, is essential for social workers.

The study described in this thesis is the first known UK based study of the lived experience of vulnerability among older people ageing with deafblindness. It was completed in two stages. First, I completed a systematically conducted literature review, to determine what was already known about deafblind people's experiences of ageing with the impairment, and what was already known about the vulnerability of deafblind people. A rigorous and systematic search found no primary studies focused solely and specifically on these topics. Relevant material located is very diverse in nature, concerns different sub-groups of the deafblind population, and makes use of different definitions of deafblindness. Study limitations, the diversity of material and an oft lack of clarity in relation to the particular group of deafblind people concerned problematised quality appraisal and synthesis of the literature. Nevertheless, the review highlights similarities in experience between those ageing with deafblindness and those ageing with other impairments.

The vulnerability of deafblind people may be considered axiomatic. An etic perspective of vulnerability evident in the literature supports this view, yet the limited literature focusing on the causes of such vulnerability largely concerns sub-groups of deafblind people other than those ageing with the condition: deafblind children and those with additional intellectual impairment. Other groups of deafblind people do describe their lived experiences of vulnerability in the material reviewed. These are often related to specific situations and deafblind people do not appear to describe themselves as vulnerable simply because they are deafblind. Particularly limited in the literature is research adopting a salutogenesis perspective, in which consideration is given to deafblind people's coping capacities. Such a gap in the literature risks perpetuating negative stereotypes of deafblind people as passive and dependent.

For the second stage of the research, I undertook a primary qualitative study. I adopted interpretative phenomenological analysis (IPA) as my research approach, reflecting my epistemological and ontological position, and the nature of the research questions. With a fellow researcher, I argue that 'researchers may shy away from deafblindness as an area of investigation because of the perception that this type of work may be loaded with methodological challenges' (Wittich and Simcock 2019:451). I had to make adaptations at various stages of the research process, to promote and enable the inclusion of deafblind people and represent their experiences authentically. This included culturally and linguistically appropriate approaches to consent and the production of participant information materials in several formats. Various recruitment strategies were used to enlist eight participants. I undertook 18 in-depth semi-structured interviews, which elicited rich data. Facilitating these interviews necessitated further adaptations, including identifying and meeting receptive and expressive communication and language needs, and adapting enabling techniques, such as the use of silence and ways of indicating attentiveness. Five interviews also involved British Sign Language interpreters, who were involved in both data collection and analysis. My decision to use interpreters was informed by a desire to 'give voice' to those who have been neglected in mainstream gerontological literature. I drew upon Squires' (2009) criteria for evaluating the management of interpreters in qualitative research, in order to maintain rigour. Acknowledging their role as co-constructors of knowledge, it was also important to render their identification and role visible. Analysis followed Smith and colleagues' (2009) iterative six-step IPA process.

Findings show how participants interpret their vulnerability as layered, describing what they feel vulnerable about, what they feel vulnerable to and when they feel vulnerable. The latter layer is predominant: the participants' experiences of vulnerability are time-limited, and situation and setting specific, and reflect Mackenzie and colleagues' (2014) taxonomy of vulnerability: inherent, situational and pathogenic. These findings strengthen arguments against the categorisation of particular groups, including deafblind people, as permanently and immutably vulnerable. Situational and pathogenic sources of vulnerability include the responses of other people at an interpersonal level. The experience of being misunderstood or perceived as incapable is observed as a shared experience among participants. Such vulnerabilities can have a negative impact on their lives, including negating their own coping strategies or the effectiveness of available support. The layers of vulnerability – about, to and when - are not discrete but interrelated. The participants' compelling stories demonstrate how they can be combined and how the avoidance of one vulnerability can exacerbate another, in an almost iatrogenic effect.

Findings also reveal how participants understand the nature of their dual impairment, and how this contributes to a sense of multiple identities. As adults ageing with deafblindness, they highlight the inadequacy of the long-standing congenital-acquired divide in the research, policy and practice communities. Their spanning of this divide may contribute to their sense of multiple identities, and the findings of this study support those of others, that deafblindness is more an experience than an identity. Central to this experience is difficulty compensating, but this difficulty transcends the inability of one sense to compensate for impairment in the other and is multi-faceted; situation and setting specific elements are contributory factors. Findings further proffer direct challenge to notions of life-long conditions as easier to manage and sensory impairment as static or stable. Participants experience ongoing difficulties as they age, and deafblindness and ageing complicate each other. Change and consequent adaptation are common experiences for participants. However, their own adjustments may be rendered nugatory if required adjustments are not made by others.

Although participants describe experiences of vulnerability, challenge, and ongoing difficulties, it would be inaccurate, and unsupported by the data, to suggest that participants lack agency or are passive actors in their experience. Participants adopt a range of practical and psychological strategies, and demonstrate creativity as they develop solutions to the challenges they encounter. Though these vary among participants, findings reveal that the ways in which they manage their difficulties, and the attributes of the care and support they value, respond to the very elements they identify as generating their felt vulnerability.

Vulnerability is a complex concept, and, though the term is used frequently in health and social care, its meaning is contentious. Seeking to integrate approaches focused on the identification of 'vulnerable groups' based on inherent characteristics and the conception of vulnerability as universal to all humanity, Mackenzie, Rogers and Dodds developed their taxonomy (Mackenzie et al. 2014a). This identifies three different sources of vulnerability: inherent, situational and pathogenic. Adding to the limited research on the lived experience of vulnerability, the findings from the study presented in this thesis further develop our understanding of the phenomenon. The three-layered conceptualisation of vulnerability emerging from data analysis – vulnerable about, vulnerable to and vulnerable when – illuminates the ways in which these sources of vulnerability are manifested in participants' lives. Though analysis reveals the place of deafblindness, as an inherent characteristic, in participants' experience of vulnerability, the three-layered approach draws attention to the identification of actual threats (vulnerable about and to) and situational, setting and pathogenic factors (vulnerable when). It highlights the non-discrete nature of the sources of vulnerability in the taxonomy, and illustrates how factors beyond deafblindness engender and influence the vulnerability experience.

While the layers themselves are similarly non-discrete, it is the 'vulnerable when' layer that dominates the participants' experiences. Though deafblind people are often identified as a vulnerable group, this finding problematises the notion of vulnerability as static, and also, therefore, the perception of deafblind people as permanently or immutably vulnerable. Data analysis reveals vulnerability as a fluid process and transitorily experienced phenomenon, dependent on different contexts; feelings of vulnerability are intertwined with times of felt safety and security. Its fluidity is further revealed by the three-layered approach, as the layers 'vulnerable when' and 'vulnerable to' are shown to interact, sometimes with iatrogenic effect. Providing empirical support for the inclusion of resilience or capacity to cope in our understanding of vulnerability, the current study shows that the ways in which participants manage their difficulties resonate with the elements they identify as generating their felt vulnerability. This suggests that resilience too is a fluid rather than static process. Strengthening the conceptualisation of resilience as fluid, data analysis shows how capacity to cope transcends inherent characteristics, such as deafblindness or one's personality, and is similarly context specific. Irrespective of individual abilities, factors beyond one's control, such as the responses of others and the unavailability of support can impact upon capacity to cope.

In the field of deafblindness, the place of inherent characteristics in the experience of vulnerability is particularly evident in the ways in which certain vulnerabilities concern either congenitally deafblind people or those with acquired deafblindness, as observed in Chapter Two. Nevertheless, the current study highlights how those ageing with deafblindness challenge the congenital-acquired impairment divide, long-standing in research, policy and practice. As such, understanding the vulnerability of those ageing with deafblindness necessitates careful examination of the multiple sources of vulnerability, particularly those beyond inherent characteristics. The three-layered conceptualisation of vulnerability can facilitate such examination.

11.2 Recommendations for Policy and Practice

Although vulnerability has a significant 'role in shaping policies and interventions… in the lives of those identified as in need' (Brown 2012:42), van den Hoonard (2018:312) argues that the nebulous nature of the concept 'makes it troublesome to operationalise'. Focusing solely on inherent characteristics as an indicator of vulnerability, risks not only disempowering older and disabled adults, but providing an inadequate understanding of the experience. There have been calls to pay more attention to the particular risks adults are vulnerable to, rather than the mere identification of certain individuals or groups as vulnerable. However, policymakers should consider adopting a layered approach in its defining of vulnerability: vulnerability about, vulnerability to, and vulnerability when. Assessment of these layers, and the way they interact in people's lives, may offer a more nuanced understanding of the experience for the particular deafblind individual and assist in determining what matters to them. Coping strategies appear to be associated with the very elements experienced as contributing to felt vulnerability. Therefore, such an approach may also enable practitioners to appropriately bolster coping capacity and provide services and support in a way valued by those with whom they work. It appears that interventions that enable those ageing with deafblindness to maintain control and demonstrate their capability are particularly important. Interventions shown to achieve such outcomes should therefore be considered for those ageing with deafblindness, and assumptions of incapability based on impairment avoided.

Wittich et al. (2017) contend that health and social care practitioners have reported a need for training in relation to meeting the needs of deafblind older adults, and others have called for greater awareness of deafblindness among both professionals and the public (see, for example, Evans 2017b). Findings of the present support such calls. However, it is important that any awareness activities or training pay careful attention not to homogenise the deafblind population, and highlight the need to transcend knowledge of the impairment and understand each unique individual. Consideration should be given to the involvement of deafblind people in training activities, such that it is centred on relationships and knowing individuals, rather than just knowledge about a particular impairment.

Finally, in supporting recognition of the heterogeneity of the deafblind population, policymakers should consider developing and expanding the categories of deafblind people currently adopted, rendering it explicit that some older deafblind people are those who have aged with the impairment. It is important to move beyond the congenital-acquired divide in this regard.

11.3 Recommendations for Future Research

The paucity of qualitative research on the experiences of deafblind people, particularly in the UK, suggests that such study on all aspects of their lives would be welcome. Nevertheless, there are challenges, both methodological and practical, in recruiting and engaging deafblind people in research, such that their voices are heard and authentically represented. A priority, therefore, appears to be determining and describing effective ways of involving deafblind people, particularly those using tactile communication methods, in primary studies and throughout the policy making process, as participants, co-researchers and collaborators. Offering more detailed descriptions of research methods in published papers would assist other researchers in the field; this work has already begun and is to be welcomed (Skilton et al. 2018, Jaiswal et al. 2020, Bacchini and Simcock *in press*).

There is potential for much further research in relation to those older people who are ageing with deafblindness. Establishing the size of the ageing with deafblindness population locally and nationally is one important next step, and may serve to increase their visibility and inform resource allocation and health and social care service planning. Longitudinal study of the ageing with deafblindness population could also enhance our understanding, as would greater inclusion in studies of deafblind people considered the ‘old old’. Recruitment of deafblind people in much later life appears particularly challenging, so should be considered as part of the ongoing work described in the paragraph above. In developing research relating to those ageing with deafblindness, the research community should seize the opportunity to bridge the congenital-acquired divide, and draw on the experience and expertise of both in multi-disciplinary study.

There is also scope for further study on the lived experience of vulnerability among other groups. While this could involve other 'impairment groups', this study highlights some of the problems of homogenising deafblind people. As such, qualitative studies examining the lived experience of vulnerability among other sub-populations of the deafblind population could offer insight into the ways the phenomenon is experienced differently among a so called 'vulnerable group'. Nonetheless, researchers should explore coping capabilities and strategies within any such study.

11.3 Strengths of the Study

There are several methods for reviewing literature. Nonetheless, adopting a systematic approach, that was thorough, replicable and transparent, enhanced rigour (Poth and Ross 2009). Providing information to practitioners and policy makers (Waganaar 1999, Taylor et al. 2003), systematically conducted reviews are now widely used to inform evidence-based social care (Sutcliffe et al. 2012, Soilemezi and Linceviciute 2018) and increasingly so in social work (Rutter 2013, Crisp 2015). However, adopting such an approach was also important for research in this particular area of knowledge, and thus adds value to the thesis. First, it ensured that the material reviewed went beyond that already known through my professional experience in the field. Secondly, compared to other review methods, systematic approaches offer 'greater breadth and greater depth' (Harden et al. 2004:798), and are known for highlighting both gaps in knowledge and methodological limitations (Waganaar 1999, Poth and Ross 2009, Harden et al. 2004). This was essential for a field of study still in its infancy (Dammeyer 2015) and helped inform my decision making when determining appropriate methods for the primary research undertaken. As recommended by the Social Care Institute for Excellence's (SCIE) systematic review guidelines (Rutter et al. 2010) user testimony was included in the review. Harden and Thomas (2005) warn that literature reviews risk reflecting the views of only sub-sets of particular populations. As the deafblind population has been unhelpfully homogenised in previous work (see section 2.3.1), adopting a systematic approach, with a clearly defined and focused question, avoided such risk. Oliver et al. (2005) observe the absence of socioeconomically marginalised young people's views in their systematic review of the health behaviours of young people. Similarly, the review reported in this thesis highlights the limited attention paid to the experiences of people ageing with deafblindness, and the particular focus on congenitally deafblind children in studies exploring vulnerability. Finally, as systematic review methodology continues to develop (Newman and Gough 2020) the review reported in this thesis contributes to the growing number of examples of the ways in which a methodologically diverse body of material can be synthesised; this continues to be an area of interest in review methodology (Crisp 2015, Soilemezi and Linceviciute 2018, Hammersley 2020, Hong et al. 2020).

Westwood and Carey (2018) maintain that an under-developed understanding of the features of ageing with impairment results in the marginalisation of disabled people in ageing policy. While the World Federation of the Deafblind (2018) argue that all deafblind people are at risk of exclusion from national and international welfare policies and development programmes, I argue that those ageing with the impairment are particularly overlooked (Simcock and Wittich 2019). As such, focus on those ageing with deafblindness is particular strength.

van den Hoonard (2018:317) suggests that 'researchers have cultural blind spots in understanding vulnerability' and therefore recommends that they spend time getting to know so called vulnerable people prior to commencing their study. This, he argues, 'helps to deal with prejudices' and 'avoid stereotypes' (*ibid.:*317). My previous involvement with deafblind people has undoubtedly proved positive: it supported recruitment, engagement and data collection activities.

A detailed account of the methods adopted and rationale for these is provided in this thesis, supporting the credibility of the findings. I was careful to identify and meet participants' language and communication needs (both expressive and receptive), to ensure accuracy of the data and, therefore, trustworthiness of the findings. The identity and role of the interpreters involved in data collection are also rendered visible. To ensure the visibility of British Sign Language itself, as both an ethical and political statement, I built upon the approach to direct quotations used by Ellis and Hodges (2013a); this approach also serves to safeguard more authentic representation of the participants' voices and experiences.

Throughout the research process, I kept a reflective diary, extracts from which are included in this thesis. To enhance my interview approach throughout the life of the study, 'process notes' were included in this diary. All interviews were video recorded, enabling careful transcription. I completed transcription myself for all 18 interviews and paid careful attention to the visual and physical elements of deafblind communication. In those interviews involving interpreters, the transcripts were checked in detail against the video recordings and discussions held to confirm accuracy and meaning. Second, and for some participants third interviews, offered an opportunity to check my initial interpretations of the first interviews, clarify meaning and probe further.

Throughout the analytic process, I kept a record of my thoughts, interpretations and decision-making. I kept records of decision making in this process, developing a research audit trail. This proved particularly useful when seeking to 'bracket' my own understandings and to focus on the data themselves. For example, on first observing participants describing their impairments separately, I did not comment on this. It was only when I wrote about and reflected upon my decision not to do so, that I became aware of my almost reluctance to explore it further. My understanding of deafblindness was as a third, distinct impairment, and these descriptions were not congruent with this understanding. Reflecting upon this in writing, encouraged me to return to the data again and ultimately, this description of their impairments as separate emerged as an important theme.

11.4 Study Limitations

The limitations of the systematically conducted literature review are described in Chapter Two.

Although statistical representation is not the aim of the primary study, the participant sample size is small. Furthermore, although I sought to recruit a homogenous group of participants, while they are all ageing with deafblindness, they differ in other ways. Differences in relation to their age, the aetiology of their deafblindness, and order and timing of onset of each impairment may all impact on their experience. Additionally, other factors in the participants' lives may have influenced their interpretations. Nevertheless, the idiographic commitment in interpretative phenomenological analysis (IPA) enabled exploration of the uniqueness of each participant and is shown in the accounts of the findings. Limiting some biographical details of participants may affect evaluation of transferability of the findings, but was necessary to maintain their anonymity.

Although there were an equal number of men and women involved as participants in the study, all were White British. Particular disadvantages faced by deafblind people from Black and Minority Ethnic Communities have been reported (Joule and Levenson 2008, Deafblind UK 2006), but their roles in influencing the experience of vulnerability were not therefore considered or explored in this study.

Finally, sharing completed transcripts with participants, a process termed 'member checking', was not possible, albeit a useful way to promote rigour in qualitative research. I did not have the resources to produce transcripts in the range of formats necessary, nor was it possible to produce a written transcript that was accessible to the participants using tactile British Sign Language, which has no written form.

Notwithstanding these limitations, this study makes an important contribution to the limited body of knowledge about both the lives and experiences of deafblind people and perspectives on vulnerability from those who experience it. It also helps to give voice to a group often excluded in both the gerontological and deafblind literature.

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APPENDICES

Health and Social Care in the community
Health and Social Care in the Community (2017) **25**(3), 813–839 doi: 10.1111/hsc.12317

Review

One of society's most vulnerable groups? A systematically conducted literature review exploring the vulnerability of deafblind people

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What is known about this topic

- Deafblindness is a complex impairment and deafblind people are considered a vulnerable population.
- Vulnerability is a contested concept, yet one which health and social care practitioners need to understand.
- A salutogenesis perspective is lacking in the literature on deafblindness.

What this paper adds

- Both etic and emic perspectives of vulnerability are evident in the literature on deafblindness.
- The perception of *all* deafblind people as vulnerable is questionable.
- Future studies of the lived experience of vulnerability among this population should explore coping, resilience and the potential of positive outcomes when one is vulnerable.

Abstract

The vulnerability of deafblind people is considered axiomatic; they are seen not only as a vulnerable group but also as one of the *most* vulnerable. This paper aims to synthesise existing knowledge to determine what is known about such vulnerability. A comprehensive literature search was undertaken between April 2013 and May 2014. The review method was *informed* by systematic review principles. An approach based on a 'hierarchy of evidence' would have reduced the amount of literature reviewed significantly, to the point where synthesis would not be possible. Included material was appraised and an interpretative rather than aggregative approach to synthesis adopted. Drawing on principles of critical interpretive synthesis, rather than being a determiner of whether material should be included or excluded, a critique of the literature is offered *within* the synthesis. Twenty-eight references were identified for inclusion, originating from the UK, USA, Australia, Continental Europe and the Nordic Countries. No empirical studies specifically examining the experience of vulnerability of deafblind people were found. However, deafblind people describe feelings of vulnerability in studies exploring their experiences more generally, and in personal accounts of living with the impairment. Literature produced by practitioners and specialist organisations also explores the topic. Deafblind people are identified as a population 'at risk' of various adverse outcomes, particularly when compared to the non-deafblind majority, and deafblind people describe being and feeling vulnerable in various situations. The literature largely relates to negative outcomes and includes significantly less exploration of positive risk taking, coping capacity and resilience. Deafblind people do not appear to describe themselves as being vulnerable as a permanent state, suggesting a need for greater exploration of the experience among all sections of this heterogeneous population, with consideration of the concepts of resilience and coping capacity.

Keywords: critical interpretive synthesis, deafblind, dual sensory impairment, vulnerability

Introduction

Deafblind people are described as 'some of the most vulnerable members of our community' (Hutton 2000, p. 3). However, there is limited research on the experience of this vulnerability among the deafblind population. While it may appear 'intuitively obvious' who is vulnerable (Mandelstam 2013), vulnerability

Full Article Available at: https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.12317

Ageing & Society, Page □ of □□. © Cambridge University Press □□□□ □
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Ageing with a unique impairment: a systematically conducted review of older deafblind people's experiences

PETER SIMCOCK*

ABSTRACT
Little is known about the experiences of people ageing with impairments; social gerontology has largely focused on those ageing into disability rather than those ageing with disability. This paper synthesises existing knowledge to determine what is known about the experiences of those ageing with deafblindness. A comprehensive literature search was undertaken between April □□□□ and May □□□□. The review method was informed by systematic review principles. A total of □□ references were identified for inclusion. No studies examining deafblind people's experience of ageing and old age specifically were found, suggesting that those ageing with deafblindness are an under-studied sub-group within the deafblind population. However, deafblind people describe ageing experiences in studies exploring their lives generally, and in personal accounts of living with the impairment. Practitioner-authored material also explores the topic. Similarities in experience were identified between those ageing with deafblindness and those ageing with other impairments: ongoing change and consequent need for adaptation; a particular relationship between ageing and impairment; a sense that whilst one can learn adaptive strategies having lived with impairment for many years, it does not necessarily get easier; and a particular relationship with care and support services. These experiences illustrate the unique nature of ageing with impairment, and challenge gerontologists to engage in further research and theorising in the field of disability in later life.

KEY WORDS – deafblindness, dual sensory impairment, ageing with disability.

Introduction

Whilst there is a body of interdisciplinary research on life transitions (Barroso et al. □□□□) and a developing interest in those ageing with disability, Jeppsson Grassman et al. (□□□□) observe that little is known about the experiences of people ageing with a range of impairments; social gerontology and gerontological social work research has tended to focus on those

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Vulnerability amongst adults ageing with deafblindness

APPENDIX C: Participant Information Sheet

I would like to invite you to take part in a research study. Before you decide whether you would like to take part, it is important for you to understand why the research is being done and what taking part will involve. Please read this participant information sheet or have someone read it to you. If you are interested in taking part, I will go through the information sheet with you again when we meet and answer any questions you may have.

Why is the research being done?

I am investigating older deafblind people's experiences of feeling vulnerable and their experience of ageing. Older deafblind people have been described as very vulnerable, but little research has been done with them about this. It is important to know about people's experiences of feeling vulnerable so we can understand how professionals can help people keep themselves safe without over-protecting them or taking over their lives. This research is for my PhD study.

Who is doing the research?

My name is Peter Simcock and I am carrying out this research. I am a part time PhD student at Kings College London. My supervisors are Professor Jill Manthorpe and Professor Anthea Tinker. I am also a registered social worker and work at Staffordshire University as a senior lecturer in social work.

Why have I been asked to consider taking part?

You have been invited to consider taking part because you are over 50 years old and have been deafblind or dual sensory impaired for most of your adult life. Up to 10 people will be taking part in the study.

Do I have to take part?

No. It is up to you to decide whether or not to take part in the research. You do not have to take part. If you do, you are free to withdraw from the research at any time without giving a reason. The decision to take part or not will not affect any care or support services you receive.

What does taking part involve?

If you consent to taking part, I will contact you (directly or through the organisation discussing the research with you) to arrange to meet for face-to-face interviews. The interviews will be at a convenient time and place for you and will last between one or two hours. There may be up to four interviews, but there will be at least two interviews. With your permission, the interviews will be video recorded. Interviews will take place in your preferred language / communication method. If you use British Sign Language or hands-on British Sign Language, I will be with a qualified and registered interpreter. Unfortunately, if you use sign language or hands-on sign language other than British Sign Language (for example, a sign language from another country) it will not be possible to provide an interpreter, owing to limited availability and limited funding availability. At the first interview, I will go through this information sheet with you and go through a consent form to confirm you are happy to take part. I will then ask you to tell me about yourself and particularly about your experiences of feeling vulnerable and getting older. There are no right or wrong answers to the questions, and you do not have to answer all the questions if you do not want to. In the second (and if more time is needed, third and fourth) interviews, I will ask about specific times you felt vulnerable. I will also discuss what you said in the first interview to check I have understood your experiences correctly. The interviews recorded on the video will then be transcribed into a written form.

What will happen if I don't want to carry on with the study?
If you take part in the research but at a later time decide you no longer wish to take part, I will not undertake any further interviews with you. You do not need to give a reason for stopping your involvement. Any data gathered from your previous interviews will be retained, but no further data will be gathered once you have withdrawn. Consent to participate will be discussed at the beginning of each interview.

Will taking part in the research be confidential?
Everything you say in the interviews is confidential, unless you tell me something that indicates that you or someone else is being, or is at risk of being, abused, neglected or hurt. Before telling someone else about this, I will discuss this with you. All names or personal information that might identify you will be removed from interview transcripts and data will be kept on password protected computer files or in locked cabinets at the University. My supervisors and researchers at the Social Care Workforce Research Unit may also have access to personal data (such as your address) so that they are aware of where I am if interviewing you in your home. This information will be destroyed following the interview.

Are there any risks in taking part?
Talking about being vulnerable or times when you felt vulnerable in the interviews may be upsetting or remind you of difficult times in your life. You do not have to answer all the questions I ask, and if you feel upset, we can stop for a break, turn off the video recording equipment or end the interview completely. I will also offer some information on help that is available if this would be helpful.

What will happen to the information / data collected from the interviews?
The video recording of the interviews will be transferred to a password protected computer file and then removed from the video equipment. I will then watch the videos, with the British Sign Language interpreter if one was present, and transcribe what was discussed. I will then analyse this data and write up the findings of this analysis. When the analysis is completed, the video recordings will be deleted.

What will happen to the results from the research?
The results of the research will be written up in my PhD thesis. I will also write articles for publication in academic and practitioner journals and present papers at conferences and social care practitioner forums. Any direct quotations from the interviews I use in my PhD thesis, publications or reports will be made anonymous. If you are interested in the results of the research, I can also share these with you in an appropriate format.

Who can I contact for more information or if I want to take part?

If you need further information about the research or wish to take part, you can contact me directly (contact details below). Alternatively, you can ask the organisation discussing the research with you to contact me on your behalf. I will then contact you with a formal invitation to participate. If you then confirm your interest, I will arrange to meet you.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by the Social Care Research Ethics Committee. A research Ethics Committee is a group of independent people who review research to protect the dignity, rights, safety and well-being of participants and researchers.

If I need to, who do I contact to report problems or complain about the research?

If you have any problems or concerns about the research or how it has been carried out, you can contact my primary supervisor Professor Jill Manthorpe. (Contact details below).

Contact Details for Peter Simcock

Email: peter.simcock@kcl.ac.uk OR p.simcock@staffs.ac.uk

Tel: 01782 294420 Textphone Users: 18001 01782 294420

Postal Address:
Faculty of Health Sciences, BG62, Brindley Building, Leek Road, Stoke on Trent, ST4 2DF

Contact Details for Professor Jill Manthorpe

Email: jill.manthorpe@kcl.ac.uk

Tel: 0207 848 1503 Textphone Users: 18001 0207 848 1503

Postal Address:
Social Care Workforce Research Unit, King's College London, Strand, London. WC2R 2LS.

Vulnerability amongst adults
ageing with deafblindness

APPENDIX D: CONSENT FORM FOR PARTICIPANTS

Thank you for considering taking part in this research.
If you have any questions please ask the researcher before you decide to take part.
You will be given a copy of this Consent Form to keep and refer to at any time.

	YES	NO
I confirm that I have read (or had read/communicated to me) and understood the participant information sheet dated 03/01/14 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions about the study and have had these answered satisfactorily.		
I understand that my participation in the study is voluntary and that I am free to withdraw at any time, without giving a reason. I understand that withdrawing will not affect any care or support services I receive.		
I understand that if I withdraw from the study, information/data collected from the interviews up to that point will be used, but no further data will be collected.		
I am aware that everything I say in the interviews is confidential, unless I disclose that I or someone else is being, or is at risk of being, abused, neglected or harmed. I understand that before telling someone else, the researcher will discuss this with me.		
I consent to the interviews being video recorded.		
I understand that a registered and qualified interpreter may accompany the researcher.		
I consent to anonymised direct quotations from the interviews being used in the thesis, publications and conference papers.		
I agree to take part in the study		

Name of Participant:

Signed :

Date:

Name of Researcher: PETER SIMCOCK

Signed:

Date:

For those confirming consent via British Sign Language or tactual communication methods:

………………………………………. [PARTICIPANT] communicates using ……………………………. [COMMUNICATION METHOD]. This consent form has been communicated accordingly and his/her consent has been confirmed in this communication method and video recorded.

Name of Researcher: PETER SIMCOCK

Signed:

Date:

APPENDIX E

The lived experience of vulnerability amongst adults ageing with deafblindness and the implications for safeguarding

INTERVIEW SCHEDULE

1. Please tell me about you.

2. Please tell me what ‘being vulnerable’ means to you.

3. Please tell me what ‘getting old’ means to you.

4. Can you tell me about what things you feel vulnerable to?

5. Please tell me about a time you felt vulnerable. (Prompts: What happened? How did it feel? What helped you?)

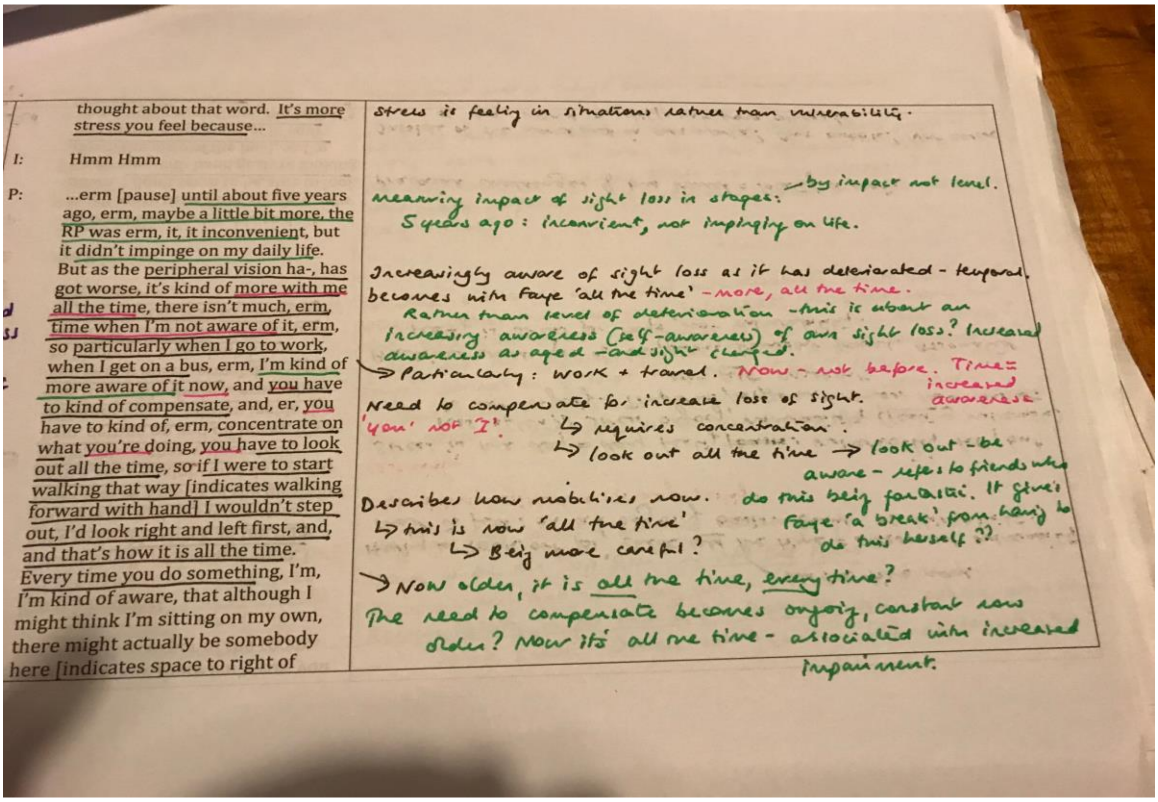
6. Can you describe how feeling vulnerable affects you / impacts on you and your relationships with other people?

7. Can you describe how you respond to feeling vulnerable? (Prompts: specific experiences and examples; How did you cope? What were the challenges? Did you seek support from others? Who?)

8. Has getting older impacted on your experiences of feeling vulnerable?

9. How do you think other people see you?

APPENDIX F: Examples of Annotated Participant Interview Transcripts



thought about that word. It's more stress you feel because...

I: Hmm Hmm

P: ...erm [pause] until about five years ago, erm, maybe a little bit more, the RP was erm, it, it inconvenient, but it didn't impinge on my daily life. But as the peripheral vision ha-, has got worse, it's kind of more with me all the time, there isn't much, erm, time when I'm not aware of it, erm, so particularly when I go to work, when I get on a bus, erm, I'm kind of more aware of it now, and you have to kind of compensate, and, er, you have to kind of, erm, concentrate on what you're doing, you have to look out all the time, so if I were to start walking that way [indicates walking forward with hand] I wouldn't step out, I'd look right and left first, and, and that's how it is all the time. Every time you do something, I'm, I'm kind of aware, that although I might think I'm sitting on my own, there might actually be somebody here [indicates space to right of

Stress is feeling in situations rather than vulnerability.

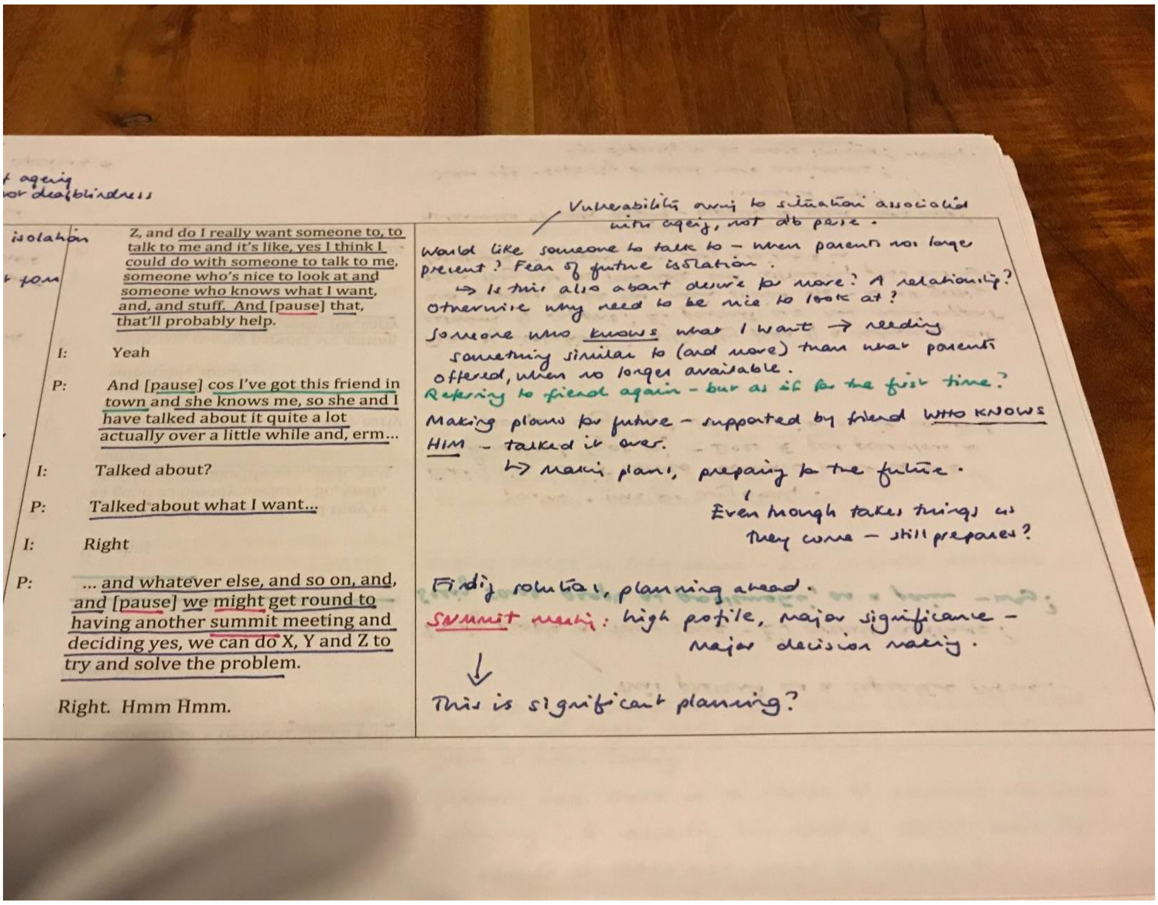
Meaning impact of sight loss in stages: → by impact not level.
5 years ago: inconvenient, not impinging on life.

Increasingly aware of sight loss as it has deteriorated – temporal. becomes with Faye 'all the time' – more, all the time.
Rather than level of deterioration – this is about an increasing awareness (self-awareness) of own sight loss? Increased awareness as aged – and sight changed.
→ Particularly: work + travel. Now – not before. Time = increased awareness

Need to compensate for increase loss of sight.
'you' not 'I'.
↳ requires concentration.
↳ look out all the time → look out – be aware – refers to friends who do this being fantastic. It gives Faye 'a break' from having to do this herself??

Describes how mobilises now.
↳ this is now 'all the time'
↳ Being more careful?

→ Now older, it is all the time, every time?
The need to compensate becomes ongoing, constant now older? Now it's all the time – associated with increased impairment.



t ageing
or deafblindness

isolation

Z, and do I really want someone to, to talk to me and it's like, yes I think I could do with someone to talk to me, someone who's nice to look at and someone who knows what I want, and, and stuff. And [pause] that, that'll probably help.

I: Yeah

P: And [pause] cos I've got this friend in town and she knows me, so she and I have talked about it quite a lot actually over a little while and, erm...

I: Talked about?

P: Talked about what I want...

I: Right

P: ... and whatever else, and so on, and, and [pause] we might get round to having another summit meeting and deciding yes, we can do X, Y and Z to try and solve the problem.

Right. Hmm Hmm.

Vulnerability owing to situation associated with ageing, not db per se.

Would like someone to talk to – when parents no longer present? Fear of future isolation.
→ Is this also about desire for more? A relationship? Otherwise why need to be nice to look at?

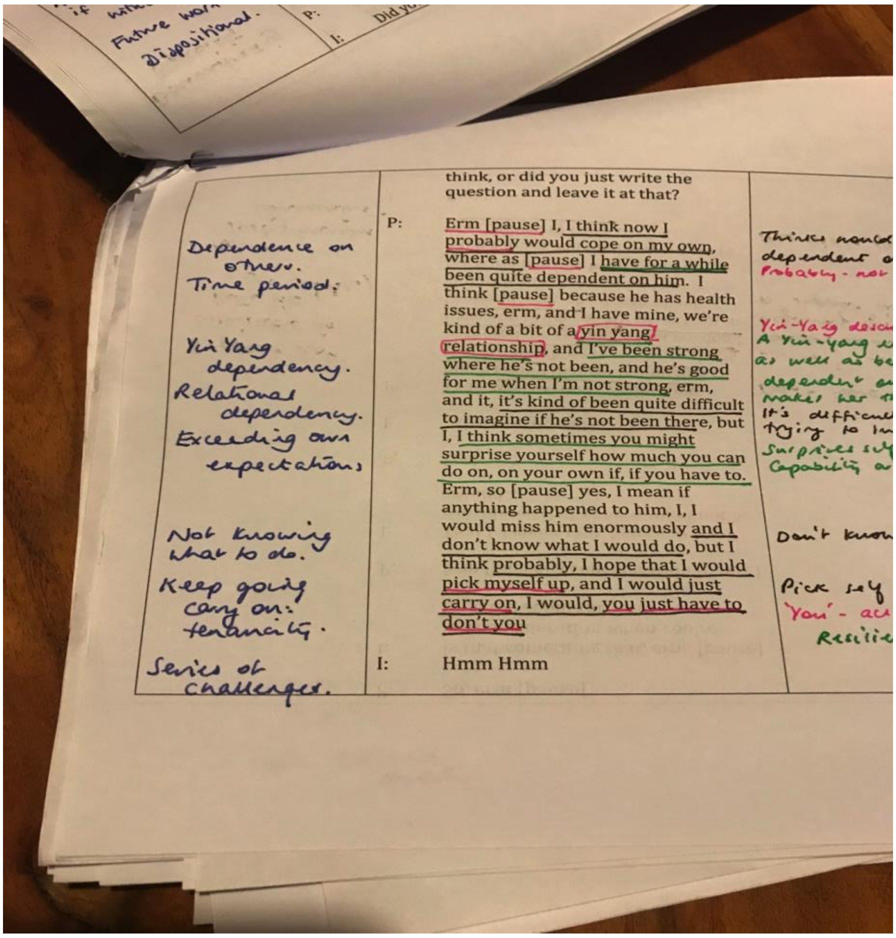
Someone who knows what I want → needing something similar to (and more) than what parents offered, when no longer available.

Referring to friend again – but as if for the first time?

Making plans for future – supported by friend WHO KNOWS HIM – talked it over.
↳ making plans, preparing for the future.
Even though takes things as they come – still prepares?

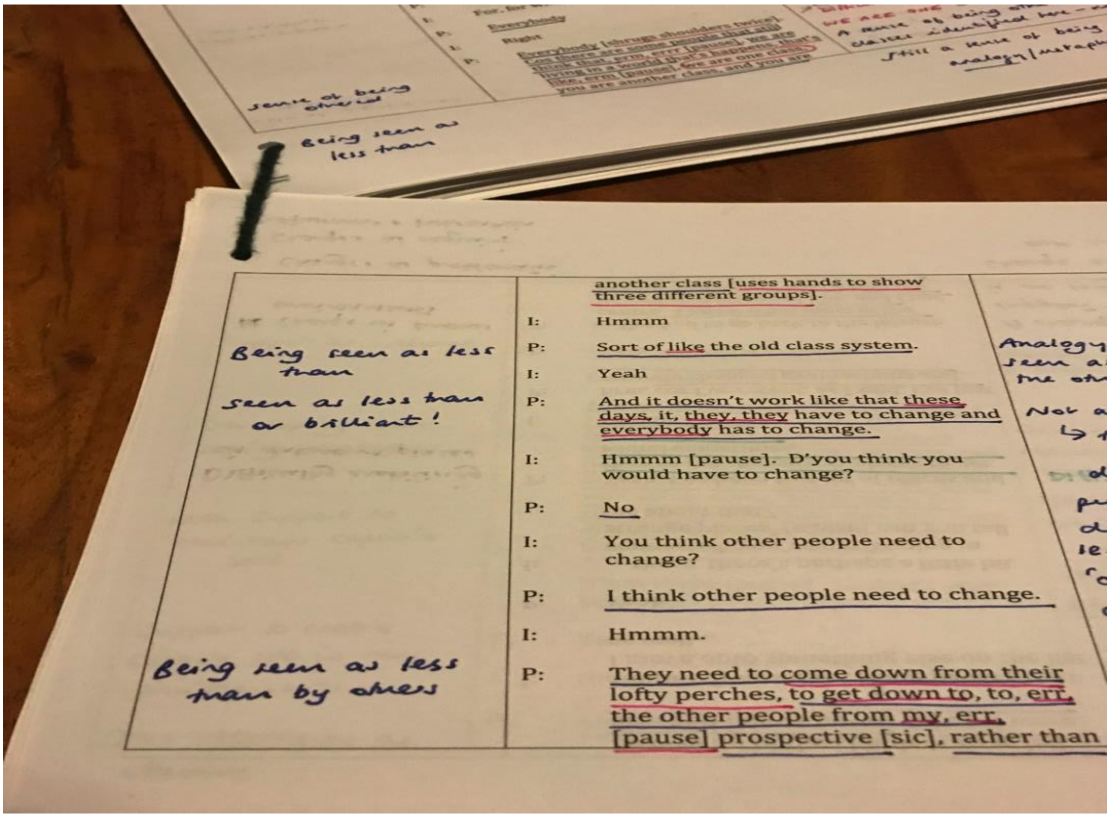
Finding solutions, planning ahead.
SUMMIT meeting: high profile, major significance – major decision making.
↓
This is significant planning?

APPENDIX G: Examples of the Identification of Emerging Themes



Future work
Dispositional.

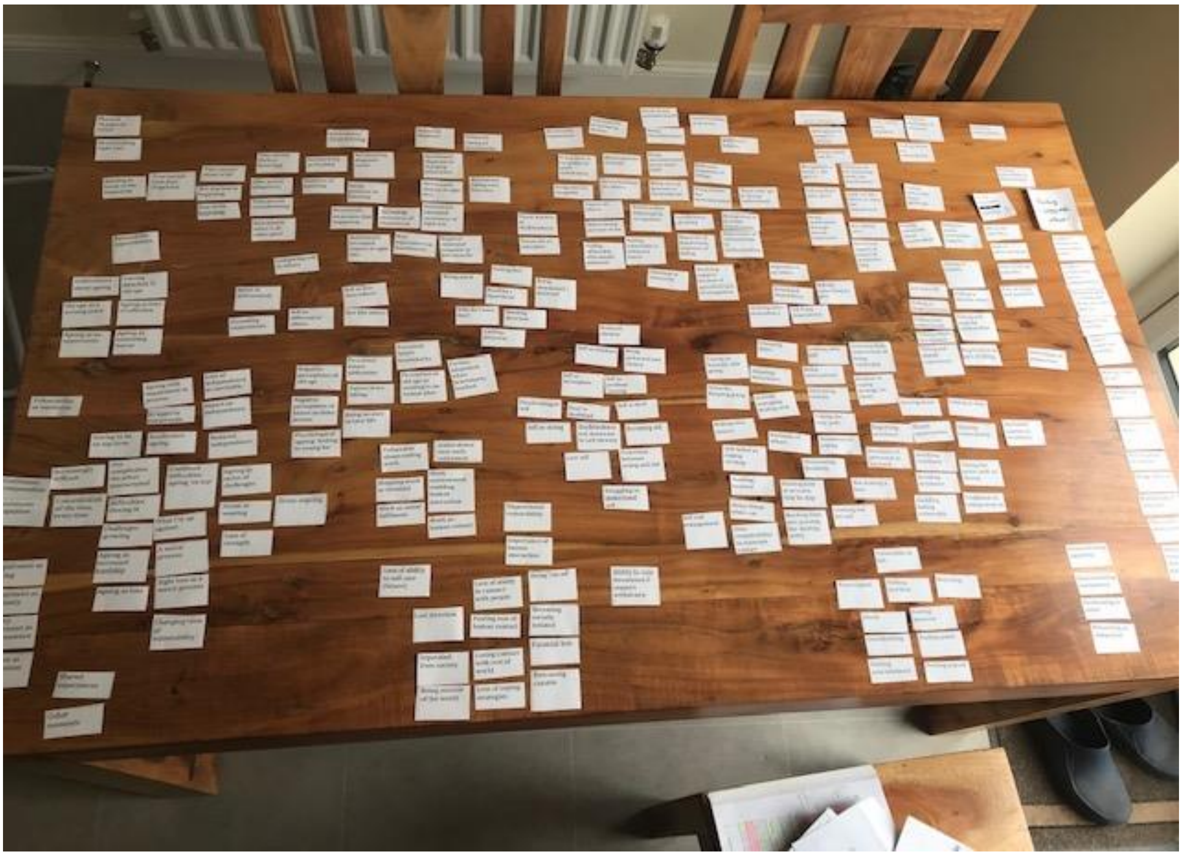
		think, or did you just write the question and leave it at that?	
Dependence on others. Time period: Yin Yang dependency. Relational dependency. Exceeding own expectations Not knowing what to do. Keep going carry on: tenancity. Series of challenges.	P:	Erm [pause] I, I think now I probably would cope on my own, where as [pause] I have for a while been quite dependent on him. I think [pause] because he has health issues, erm, and I have mine, we're kind of a bit of a yin yang relationship, and I've been strong where he's not been, and he's good for me when I'm not strong, erm, and it, it's kind of been quite difficult to imagine if he's not been there, but I, I think sometimes you might surprise yourself how much you can do on, on your own if, if you have to. Erm, so [pause] yes, I mean if anything happened to him, I, I would miss him enormously and I don't know what I would do, but I think probably, I hope that I would pick myself up, and I would just carry on, I would, you just have to don't you	Thinks nowa dependent o Probably - not Yin-Yang desc A yin-yang as well as be dependent a makes her t It's difficul trying to im Surprises sel Capability a Don't know Pick sel 'You' - ac Resilie
	I:	Hmm Hmm	

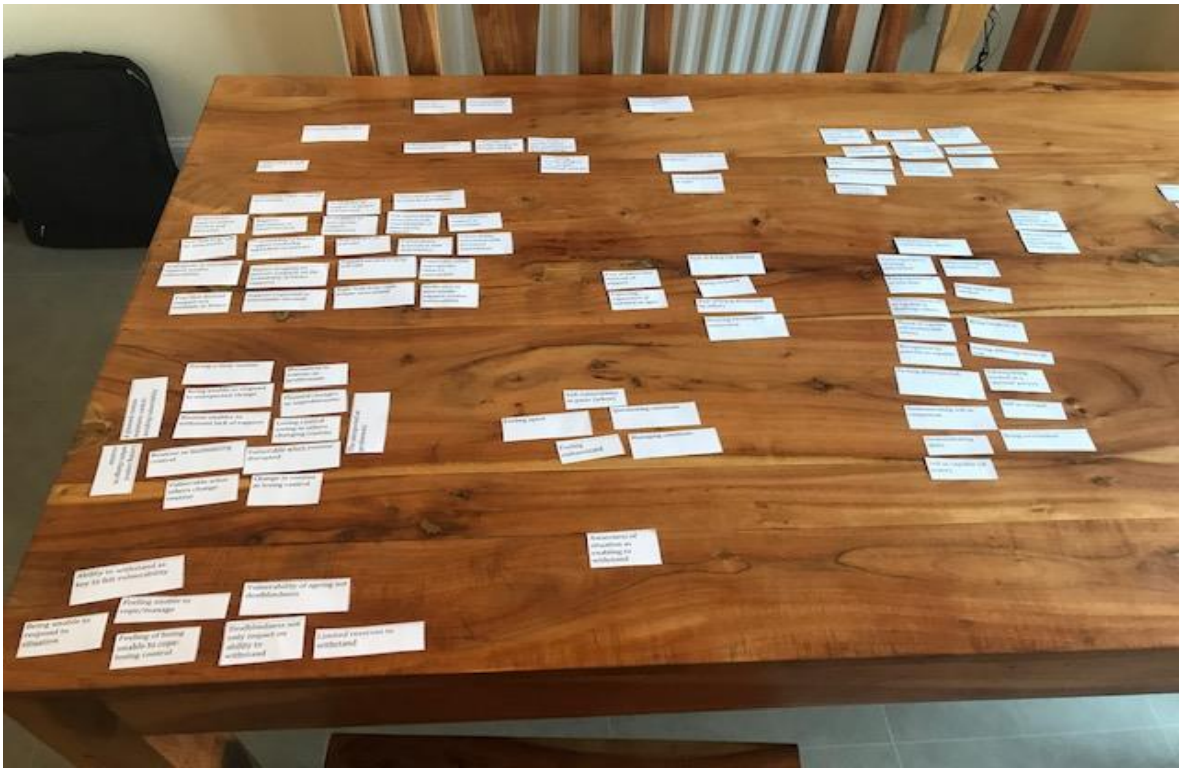


	I:	For, for w	WE ARE ONE A sense of being othered here classes identified
	P:	Everybody	
	I:	Right	
Sense of being othered Being seen as less than	P:	Everybody [shrugs shoulders twice]. Cos there are some people that still think that, erm, errr [pause], we are living in a world that's happens, that's like, erm [pause], we are one class, and you are	Still a sense of being analogy/metaph

		another class [uses hands to show three different groups].	
	I:	Hmmm	
Being seen as less than	P:	Sort of like the old class system.	Analogy seen a the oth
	I:	Yeah	
seen as less than or brilliant!	P:	And it doesn't work like that these days, it, they, they have to change and everybody has to change.	Not a ↳
	I:	Hmmm [pause]. D'you think you would have to change?	
	P:	No	
	I:	You think other people need to change?	
	P:	I think other people need to change.	
	I:	Hmmm.	
Being seen as less than by others	P:	They need to come down from their lofty perches, to get down to, to, err, the other people from my, err, [pause] prospective [sic], rather than	

APPENDIX H: Searching for Connections Across Emergent Themes





APPENDIX I: Table 13 Themes for Each Participant

Participant Mike: Table of Super-Ordinate Themes & Themes

Themes	Page/Line	Key Words
Fearing Particular Dangers		
Identifying specific dangers and risks	8.47/11.3	tree being blown over/ very dangerous
Fear of danger	11.21	I'm frightened of the danger
Risk of physical harm	11.8/33.25	can get cut easily/ make you very ill
Risk of damage and disaster	9.2/11.17	can do a lot of damage/ can catch fire
Feeling frightened *when*: fear and worry time and situation specific	8.46	*sometimes when* it's very windy
Worry and Fear as time limited	6.45/ 14.25	a few times/don't feel worried… again
Lack of control over immediate environment	25.21	I've lost quite a few things
Feeling controlled	5.42/6.14	being told what to do/ bossing me
Feeling that losing control	5.38	can't get my own way
The immediate environment being unknown	7.1/ 7.14	hear the thunder… can't see/ behind me
	7.24/ 10.47	can't see where it's coming from
	23.16/35.18	makes me jump… can't see when
Losing privacy	8.9/9.39	not your business/ talking about my…
Losing autonomy	6.18/7.38	staff want me to do what they want
Support no longer being available	16.17/32.30	job just went away/ it's not fair
Support enables to withstand	23.12/33.12	I feel alright if I hold onto the staff
Help removes risk	34.22/34.30	I get help… I might burn myself
Getting used to reducing fear	9.7	but now I've got used to… I've got used
	14.11-20	getting used to it… not as frightened
Being perceived as incapable		
Being described as incapable	8.22	can't handle my money very well
Being treated as incapable	25.48	telling me off you see
Being treated like a child	12.17	shouting at me…way I'm… treated
Needing help with some things equated with needing help with all things	8.10/25.49	the money's got nothing to do with you
Demonstrating self as capable		
Demonstrating self as skilled	17.43/26.40	to do wood work, pottery, gardening
Demonstrating knowledge	15.10/16.25	teach people braille work/ traffic lights
Self as capable and contributing	25.7/ 30.13	learnt something new/ to the business
Self as savvy	52.19	it as about £100 but I paid £35
Presenting self as independent adult	21.18	I'm getting my own car soon
Educating others	1.39/15.10	about deafblind people at University
Demonstrating capable self irrespective of having help	49.2	I go… I go… then I go
Sight loss affecting enjoyment not ability	46.48	I can still do it but… used to like it

Recognition of talents valued	30.21-30	I got a certificate and… trophy… happy
Feeling and Managing Negative Emotions		
Emotional impact of sight loss	2.17/46.48	wish it didn't /now can't see I get fed up
Impact on mental health and well-being	5.37/16.27	I get depressed sometimes
Feeling angry and upset	5.38/6.26	very upset/ makes me a bit angry
Feeling anxious	11.47	I've been anxious quite a lot
Feeling sadness	3.48/16.26	not very happy
Small actions to manage emotions	10.24/12.31	listen to music… get coffee, or smoke
Talking to staff to manage emotions	7.37/9.30	I talk to that staff/ about the… upset me
Taking action to calm self down	7.32/30.2	have a cigarette…calms me down
Letting things go	14.45/17.21	I say 'Balls to them'!/ I just left it
Sensory Impairment as Identity		
Former self as sighted	13.12/46.41	I was young, when I could see… see
Former self able to see and hear	1.23	I could see and I could hear... but
Younger sighted self	3.15	when I was younger, when I could see
Deterioration to point of *being* blind	1.19	I went… that caused me to go blind
Deterioration resulting in changed identity	3.16/5.32	I'm blind now/makes me… lot different
Identifying as blind	2.17	four of us blind
Identifying as deafblind	3.7	what it's like to be deafblind
Describing others by impairment and communication method	2.12-35 27.32-41	are fully blind… three can hear… can see, but he can't hear/he can lip-read
Comparing impairment with others	2.21	deaf and blind like myself
A thing called Usher	1.19	And… I got a thing called Usher
Focus on Sight Loss		
Impact of sight loss	13.13	now I can't see I get frightened
Impact of sight loss more evident	47.4	Because I can't see what I'm doing
Need for help associated with sight loss	34.13	we all get help, except… can see to do
Inaccessible activities in single sensory service	28.40	don't play that… you have to see the ball
Sensory Impairments as separate	1.10/3.17	deaf and blind/ blind and partly deaf
New Challenges and Increasing difficulty as ageing	3.36	since I got older, it's gone worser
Experiencing other health conditions	25.3	new tablets… can't sleep very well
Increasing difficulty following deterioration	4.43/46.41	things became a bit hard/ like I used to
Deterioration in sight increasing dependence	34.1	I used to make it… The staff do
Difficulty compensating	3.32/4.16	hear the traffic, but… can't see to cross
Limitations of touch	47.6	you can't touch them in the shop
Increased dependence on staff	22.35	I go with a member of staff, everywhere
Communication with other deafblind as complex	5.14-23	talking to me while I'm… fingerspelling
Others lacking required skills	5.4	people who can't do fingerspelling… I don't talk to them

Experiencing change and needing to adapt		
Deterioration in functional hearing and vision	4.48	hard to see and it's hard to hear
Deterioration in hearing	1.23	now I've gone… half deaf
Change in hearing aid use	1.24	used to wear one… started to wear two
Undesired change of accommodation	18.21	closed down…upset and unhappy
Experiencing changes in accommodation	18.16-25	then I moved to/ so I've been in
Staff changes inevitable	19.10/19.41	she left.. lot of changing/ left as well
Losing job	1.40/15.15	it's finished now/ closed down
New knowledge needed to adapt	3.27	how to use traffic lights
Gaining and learning new skills	1.26/ 26.19	started learning braille/ learning to use
Adapting to deterioration	1.27	typing and reading braille
Adapting to the use of support	3.27	get on very well with being guide
Needing others to adapt	4.49	when people don't talk loud enough
Using mixed communication methods to socialise	1.38/27.29 27.47	doing sign language/ a bit of fingerspelling to my friend/ lip-read to
Adapting communication to meet others' needs	45.3	he can see me talking… but not as
Adapting by using touch	47.5	can't see them. But I can feel them
Adapting by choosing alternatives	28.49	I don't… I'm quite happy, I can play…
Getting used to	13.21/19.47	After a while, I get used to it/ got used
Developing own coping strategies	13.29	I put my headphones on and listen to..
Own problem solving and solution finding	21.27 26.7	Taxis a lot of money… using the bus make sure what note I take out
Maintaining Control and Autonomy		
Being in control	32.25/37.28	like to do what I like / do my own thing
Having a routine	33.4/48.45	first of all, Monday…/ morning, I do…
Acting on own decisions	18.3/26.46	I didn't want to do it/ I don't go
Using support not negating autonomy	31.13	I tell them, turn left, you turn
Being helped *with* not cared for	4.26/32.42	with the washing…. with the cooking
Supporting is working *with*	26.6/31.37	I'm still working with… we go to the
Needing flexible hours of support	49.44	Take all the hours off Wednesday and…
Raising concerns	8.10/10.2	so I've told [Senior Member of Staff]
Using Services		
Help positive and valued	3.23/4.31	like being helped/ it's very good
Accessing financial support	42.11	I've got my car and I go out
Using combined support: human assistance and aids	30.35 31.11	I hold them on their lower arm and use my stick
Having help with domestic tasks	4.21/32.42	help making the bed… washing and the ironing… the cooking
Social Interaction Improving Well-Being		
Enjoying social interaction	1.46/19.5	I enjoy it/ happy… writing… to me
Desiring social interaction	10.22/32.31	on… own… Not very happy/meet
Attendance at Deaf Club as social interaction	1.45/27.16	I go to a Deaf club

Socialising with other d/Deaf & deafblind people	1.38	I enjoy… talking to deafblind people/ I talk to [deaf people]
Valuing social interaction with staff	20.11	I play games in the staff flat
Losing job as lost social interaction	15.31/15.48	don’t see the people I used to see
Managing Relationships		
Relationships with staff valued	26.29-32	very happy to see [staff] back
Relationships with staff as friendships	19.40/45.31	good friend with [staff]
Arguments with staff	7.34	have an argument with staff
Withdrawing from staff	12.41	I don’t talk to that staff after a while
Change of accommodation impacting on relationships	18.44	had a girlfriend… don’t see her…because… not in [accommodation]
Confusion in relationship boundaries	24.45	wanted to make love… you can’t do that
Sense of belonging	29.23	how long I’ve been known at Deaf club
Being left	25.5/25.1	since you’ve left me/ you left me
Not seeing self as old		
Old people: a discrete group	27.2	old people… deafblind people normally
Old people are older than self	37.24	older than myself
Chronologically defining old people	27.8/48.25	old people mean… like 60, 70, 80
Associating activities of no interest with old age	27.4/37.20	for old people… I’m not interested in… that sort of thing/ because it’s for old people really

Participant Celia: Table of Super-Ordinate Themes & Themes

Themes	Page/Line	Key Words
Cumulative impact of previous experience		
Past experiences informing felt vulnerabilities	4.8/ 8.32	the past experiences…/ never again..
Vulnerability as being worried about	11.31	I'm only a bit worried about…
Vulnerability to particular negative outcomes		
Vulnerable to specific harms	5.37	bump my head
Fear of being a victim of crime	15.1	intruders coming in
Fear of being controlled	12.25/24.7	people controlling me/ pressurise me
Fear of losing control	7.1-16	I don't approach… it gets worse
Fear of further sight loss	4.25/ 26.22	my vision, it's terrifying/eyesight
Fear of being a burden	2.28/ 11.31	daughter… take it in turns/ burden on
Fearing cognitive decline	4.21/31.5	mind would go downhill/ deteriorate
Fear of increased dependence	30.24	don't want to keep on asking people to
Felt vulnerabilities informed by the experience of others	18.23/ 27.16	old friend of mine… She explained to me/ I've heard from [friend]
Feeling vulnerable *when*: vulnerability as time and situation specific	9.8 / 16.39	That time…/ when I got… felt relieved
Felt vulnerability not constant	2.29/ 4.13	feel safer… Spot on!/ When I'm reading
Increased felt vulnerability with age	2.15	Vulnerable. Vulnerable.
Feeling vulnerable when alone	2.25/ 3.15	I didn't feel safe /by myself/when alone
Crossing roads	3.15	crossing the road
Whom I am with	20.11-24	prefer my daughter to… guide… trust
Lacking awareness of the immediate environment	1.41 / 2.47 4.5/ 15.1	what's going on [signed to self]/ at the door… surprised/ from behind, I can't
Small things a reminder of deteriorating vision	5.40/ 6.10	get really frustrated…but why me?
Unplanned change in routine	9.15	Fine… but that time… a different way
Experiencing communication breakdown	7.10	there are breakdowns
Lacking or losing control	7.16/ 19.40	it gets worse, worse/ what food. No, no
Increased dependence threatening autonomy	5.1	not ready for that… do it myself… fine
Losing ability to withstand	3.47	older, I can't assert myself like before
Self as 'easy target'	15.14	old lady…deafblind… I'm an easy target
Support being unavailable: multi- faceted	15.42-45	what I was saying… no point writing it
Support unavailable: impairment unrecognised	9.25	didn't have my cane… walking past me
Support unavailable: unable to ask	9.18/ 15.43	I couldn't ask / couldn't make people
Availability of support reliant on communication	16.46 / 17.39	Hoping that someone could sign / I was surprised he could sign
Feeling and being seen as incapable		
Early experience of Deaf oppression	1.14	were not allowed to sign…awful
Sight loss as something wrong	1.28	something was wrong
Being seen as incompetent	3.36	people say [NMF-angrily] You've got to

Being perceived as stupid prevailing	13.48/14.7	Think I'm stupid/ Deaf… are stupid
Challenges to self as capable adult	21.24	feel like a baby, I'll need a bib soon
Feeling incapable	6.9	feel like you can't do something
Seeing self as incapable	5.38	It is stupid… I can't find things
Questioning own capability	10.11/ 19.13	said things right?/ maybe I… wrong
Self as less capable	6.20	angry… why can't I see that
Being Able to Withstand		
Able to withstand if not alone	4.14-20/5.47	my daughter's here, I'm fine… better
Being in known places with those who understand	18.31	here with my daughter… familiar, and we are able to communicate
Support available ends felt vulnerability	1.47/5.47	she signed hello… I felt relieved
Knowing support will be available enough	16.46/ 18.2	able to help me/knew wouldn't arrive
Needs understood and met, vulnerability not felt	16.25/ 37.2	he could sign… fantastic… so relieved
Understanding avoiding perception of incompetence	14.5-8	prefer to be with people who can understand me… I can't see
Asking for help in a safe space	9.30	Please could you help me tell my…
Remaining in control when at home	19.4	When I'm here… I can do what I want
Being known, being understood	22.14	Knew me… she was talking to me
Importance of being understood	27.10	understand me, which is good
Positive impact on establishing communication	9.39/22.19	I was… relieved/ things got better
Usher support: shared identity and understanding	28.36	it's fantastic…. people the same as me. They sign, use facial expression
Recognition of Usher, improved support	27.41	someone who knows… Usher
Increased awareness of Usher	44.23	the past there was no Usher, but now it's improved
Desiring and maintaining control		
Desiring control and autonomy	4.21/ 14.26	want my computer / want self-control
Remaining in control	14.15/28.11	my own…routine… at home… control
Maintaining control by maintaining independence	3.28 / 29.46	independent, makes me feel good / I've got my iPad, and she's asleep
Maintaining control to withstand in future	33.23	I have to be… in control, in the future
Establishing communication as regaining control	1.47/ 9.39	she signed… I felt better by that
Maintaining control using human assistance	31.35	person to be with me… we're the same
Maintaining control when accessing help	21.20	I prefer us to take the same steps
Recognising the value of help	3.30	I thought… 'that's really easy'
Making own decision to accept help	3.22	found a friend… to help me
Use of support not negating autonomy	14.27/ 20.48	we agree…control through discussion
Self-directed support	24.8/ 35.24	It's what I want… that's fine/ I choose
Help with, not taking over	20.49	can you help me, is this card… a big help
Taking Action to Protect Self		
Self risk management	15.13/24.8	wouldn't let them/had that discussion
Taking own actions to reduce risk	3.5/ 15.1	lock, lock, lock everything/were locked
Slowing down to protect self	24.26f/25.31	cant' keep going out/ take things slowly

Own strategies to reduce risk	20.22	my coins in the purse… away in my bag
Maintaining contact to prevent cognitive decline	30.44	I use WhatsApp… My mind would…
Avoiding situations	13.49/22.23	I'll just leave it…/ rather than going to
Avoiding communication breakdown as iatrogenic risk	7.10	Breakdowns… I sit here reading, that's good *enough*
Demonstrating self as capable		
Self as capable and competent	9.48/ 11.32	driver was stupid [not me]/ I… help
Seeing self as capable	14.26/33.2	I know… what to agree/ I'm not stupid
Sight loss impacting on enjoyment not capability	12.1-5/21.7	I look around but miss things/ I can see… but sometimes the tiles fall
The Emotional Experience of Vulnerability		
Feeling not being vulnerable	3.2	my grandson… it was him
Felt vulnerability difficult to explain	10.25/13.41	anything?/ What can I say?
Feeling upset	16.17/25.40	I was upset / and get upset
Feeling anger	1.43/5.38	I felt angry/ get really angry
Expressing anger physically	1.43 / 5.40	wanted to hit them/ I kick things
Feeling nervous	16.33	I was nervous
Feeling embarrassed	3.20/21.22	NMF-feeling small…awful/embarrassed
Feeling overwhelmed	9.36	I felt overwhelmed
Feeling frustration	4.27/ 5.9	I was feeling frustrated/ get frustrated
Why me? Feeling resentment	4.26/ 5.41	Why me? Other relatives aren't like this
Maintaining control of emotions	25.41	I'd try… and control my feelings
Protecting others emotionally	27.7	try and stay cheerful for my daughters
Fear of the Future	4.25	the future…. it's terrifying
A poor prognosis	1.33	your sight is getting worse
Usher as non-curative	11.30	there's no cure, I know, I know
Future as unknown	4.40/ 26.24	uncertain about the future/ don't know
Future as increased dependence	4.47	relying on other people…
Expecting deterioration in the future	4.47/ 11.22	in the future, I will be worse/ it will
Future self expected to be worse	4.47	I will be worse, I know that
Avoiding thinking about the future	4.39/5.11	trying to forget about the future
Deafblindness misunderstood and unrecognised		
Fear of being misunderstood	14.5	prefer… people who can understand
Feeling misunderstood by the Deaf Community	25.35	They don't understand
Single sensory impaired misunderstanding	27.42	Deaf and blind people…don't know
Misunderstanding of needs as *older* deafblind person	17.43 24.45	don't know how to help/ what [communicator-guide] expects… I just
Communication difficulties causing misunderstanding	8.32/ 13.48	person talks back/ it's communication
Being understood more than a communication	14.5	can understand me, understand my

matter		situation
Avoiding misunderstanding as prevailing	7.2-11	stop…watch them…good enough
Behaviour misunderstood as impairment unrecognised	3.16-21 3.35	purpose… I felt awful… my eyesight isn't good / someone taps my shoulder
Deafblindness as invisible impairment	27.35-6	it looks the same… you look fine
Usher unrecognised	1.31	they didn't now about Usher
Deafblindness not recognised (even with visual marker)	11.40/ 27.35	they don't recognise/ have cane… they're not aware of that
Overwhelming for others	7.42	sorry to say that… right… I'm sorry
A Mixed Identity	27.41	I'm Deaf, I'm blind and I've got Usher
Identity as Deaf	3.38/ 22.15	I'm Deaf/ I was a Deaf mother
A positive Deaf identity	1.11-3	Deaf… it was nice, same as everyone
Cultural and linguistic affiliation as Deaf	18.40	Deaf. Strong BSL user
Deaf as identity, sight loss as impairment	2.7	same…. Eyesight worse
Shared Deaf identity	2.3	life was the same as the others
Sight loss as marker of difference	1.17/ 4.26	I'm different from the others/ only one
Identity as disabled	27.37	I'm disabled
Identifying as deafblind to the Hearing	37.1	because I'm deafblind
Usher Community: a new place to belong	28.37	and they accepted me
A changing relationship with the Deaf Community		
Early engagement with the Deaf community	1.11	I went to Deaf school
Difficulties at Deaf Club	22.20/25.22	Didn't like it… still didn't like it… I left
Difficult relationships with Deaf friends	2.32	don't get me started
Being misunderstood by the Deaf community	25.25	Deaf people really don't understand
Withdrawing from social interaction at Deaf Club	7.2	now change, I don't approach them
Withdrawing from the Deaf community	4.22	not the other Deaf people
Mutual disengagement from Deaf Club	25.42	I've given up. No one phones… no one
Experiencing deafblindness as multi-faceted		
Impairments as separate	15.1/ 27.1	I can't hear / My eyes. My eyes.
Emerging sight loss in childhood	1.17	at the age of nine or ten…
First experience of deafblindness	1.42	I couldn't see anything
Focus on sight loss	2.30/ 27.1	my eyesight getting worse/ my eyes
Increased difficulties owing to sight loss	2.19	I was dropping things… feeling worse
Being unable to compensate	4.6/ 25.23	have to look round/ it's impossible
Difficulties compensating as multi-faceted	8.27-34/12.9	can't lip-read Hearing people/ bumpy
Experiencing deafblindness as more than hearing and sight loss	2.23/2.46 2.49/ 8.30	the door doesn't open fully / he wouldn't turn around/ please…move
Increasing experiences of deafblindness	4.48	future…. doing manual
Environmental impact on vision	2.45/ 9.17	I'm able to see, but… not… if not open
Environmental impact on alternative communication	16.33	There was a light, so I could… write

Ageing complicating deafblindness		
Additional age related sight loss	2.9	then I developed a cataract
Age-related changes in social circumstances	2.18	I was living alone here
Experiencing and expecting Increasing difficulties as ageing		
Ongoing deterioration over time	21.1/ 27.1	really difficult/ for a long time it's been
Cumulative impact of gradual deterioration	7.30	really silly but [multi-channel: damn]
Gradually increasing difficulties	3.30 /20.41	things getting worse/ wasn't able to go
Increasingly difficulty associated with deteriorating vision	22.47 21.23	before I could see… now I need to ask/ I'm unable to see that…getting worse
Increased dependency associated with deteriorating vision	30.17	see if I can see it… I want to be able to do it myself
Not 'getting used to'	27.1-3	won't get better… it's awful… awful
Increased loneliness	2.21/20.41	70… I was… lonely/ becoming lonely
Difficulties mobilising alone	11.41	on my own my mobility is unbalanced
Expecting things to be harder	6.9	can't do something… the future
Expecting further deterioration	4.46	I will be worse than I am now
Young self as independent and strong	3.46	I was independent, I was strong
Later life as a time of development		
Learning new skills	29.15	showed me typing… I was typing
Taking up new hobbies	29.19	finally, it was my hobby, making cards
Desire to remain physically active	12.9	so I can use my legs
Slowing down as a result of sight loss not age	25.27	my body's fit… but… have to take… time
Keeping up to date with technology	29.35	now I've got the iPhone, so I've got two
Experiencing change and making adaptations		
Change as all encompassing	7.3	my life's changing
Change in communication needs: one to one	22.22	comes here and talks with me
Change in receptive communication	25.24	being close to do hands on is… better
Deterioration in vision	1.27/2.8	vision was worse/ was deteriorating
Increased awareness of deteriorating vision	1.22/ 26.31	noticed things had changed/ It's got
Benchmarks in deteriorating vision	26.29	the last time, I could read with both
Benchmark: when help was needed	11.12	came at the right time… it got worse
Positive change: improved vision	2.17	could see much clearer after that
Change in personality	1.22	I became withdrawn
Making adjustments in earlier life	1.23	I was reading… They were…playing
Slowing down as adjusting	3.48	take my time…go slowly
Adjustment takes time	5.1	I'm not ready for that yet
Using mixed communication methods	8.27/ 9.30	rather people write things down
Adapting communication methods for others	8.30	I had to keep writing things down
Making environmental adaptations	29.44	have to turn all the lights out to see it
Adapting by compensating activities	28.42	I can't travel far, but I can read about it

Keeping Going		
Having determination	32.25	I am determined, I can do it
Having tenacity	2.2 / 16.14	I carried on/ I tried again/ to be brave
Using residual vision	16.10	I saw a blue lantern
Taking one step at a time	4.40	When it's here, I'll discuss it
Taking time out	4.28	hold on, leave me alone
Positive thinking	6.25	change my way of thinking
Avoiding negative thinking	4.31/6.24	I think about something/ other things
The helpfulness of the 'small things'	18.2/ 33.40	a cup of tea… lovely/ I have wine
Having a sense of humour	21.10/ 33.42	[laughs] You took the wrong one out!
Seeking own solutions	3.21	We'd better do something. So we…
Own problem-solving actions	9.28/ 12.5-8	Right, that's the police/ better to have
Taking time to build psychological strength	4.30	build up my strength, hold on
Having hope in the face of a feared future.	44.24	so the future, hopefully, that will get better for me
Experiencing and Expecting Ineffective Support		
Inappropriateness of mainstream older people's services	18.33/ 19.29	care home staff are stupid / I'd become very lonely
Older people's settings inaccessible	19.30	wouldn't be able... conversations
Care Homes perceived as controlling	19.4/ 30.6	have to go by a routine/ wouldn't give
Expectation of care home staff misunderstanding	27.11	understand…old people's home… no
Deafblind support as for younger people	28.39	no one the same age
Equipment to help, hinders	3.3/ 8.29	door is not suitable for me/ face dark
Support Perceived as Positive		
Help positively received	3.25/ 20.45	Fantastic/ happy…fantastic
Being known helps	3.38	she knows me, and knows I'm Deaf
Help avoids misunderstanding	3.25	I feel comfortable… I don't want to ask
Communicator-guide support as positive	5.17	makes a big difference… I'm pleased
Using combined support: family and formal (specialist)	4.23/ 5.16 20.44	they both help me / found a communicator- guide
Having someone on my side	12.28-35	better with her... someone with me
Availability of trusted support	20.23	because I always trust my daughter
Using online support	28.34	a website…Usher Support Network
Using mainstream technology	29.31/30.11	the iPad… had a look & we bought one
Technology facilitating connection and involvement	30.34-40	with the outside world…fantastic / cheers me up… have you received this

Participant Faye: Table of Super-Ordinate Themes & Themes

Themes	Page/Line	Key Words
Levels of vulnerability: General – feeling vulnerable about		
Catastrophes	23.8	nervous of catastrophes
Job	6.28	about your job
The future	6.28 / 19.41	about your future / a long way away
Being misunderstood or unrecognised (40.34)	14.27 / 8.45	what is she doing/ they would struggle
Relationships with others	27.47 / 28.7	worry… friends important
Being adrift or lost	21.49	wanting to hold on
Levels of vulnerability: Specific outcomes – feeling vulnerable to		
Unable to survive	23.21	how would I fare?
Nature of ending work	24.21 / 38.5	Any mistakes yet / that point
Early retirement (forced)	3.49	forced to stop… the work I do now
Financial loss	4.23	lose my financial independence
Fear of falling (in later life)	13.22	don’t fall over so easily
Loss of ability to self care	19.22	losing… ability to look after self
Loss of ability to connect with people	19.24 / 19.32	able to connect with people /reach out
Social Isolation	19.20	losing social interaction
Being on one’s own in later life	27.45	very much on our own in old age
Losing contact with rest of the world/human contact	19.25 / 19.32	being cut off / own bubble / own world
Loss of coping strategies	2.46	lose those thing…help you overcome
Support being unavailable	27.37	don’t really have much family
Remaining capable	19.24 / 19.44	being useful / simple things shopping
Misunderstanding of needs	12.39	I told you I can’t see
Being seen as inconsiderate	32.35 / 40.43	people thinking I’m ignoring them
Being seen as incapable or incompetent	4.24	show I’m capable of working
Making a fool of self	21.48 / 32.39	a bit stupid / not responding correctly
Reduced identity	18.7	this disabled person
Unknown responses to telling	32.44	how they’re going to take it on
Non reciprocal dependency	28.7	a one way street
Not being seen as having something to give	28.11	get other things from the friendship
Overwhelming for others	9.9 / 24.17	can't take/ not able to accommodate
Others nervous of me	42.10	I think they’re a bit nervous of me
Physical Harms	7.2 / 7.3	might hurt yourself
Levels of vulnerability: Feeling vulnerable when (specific experiences)		
Time limited	21.34 / 23.3	just in that moment / only a short spell
Support withdrawn or absent	21.32	the crutch had been taken away
Support needed not available	6.46-49	people who are not looking out for you
Being abandoned or deserted	22.20 / 21.31	don’t leave like that again / abandoned

Dependence on others	27.10 / 21.34	dependent on him / him…to help me
Negative reaction or response of others	7.24 / 12.38	they were impatient / didn't like me..
Out of sphere of control	51.31 / 7.30	out of my elements/what to do with..
Being 'othered' or marked out as different	8.30 / 8.19	why is… she not like everyone else
Feeling at a disadvantage	7.41	very much at a disadvantage
Being in unknown places	6.19	I don't know places
Being with unknown people	6.19 / 6.40	situations I don't know people
Not being known	6.31	people who don't know you very well
Vulnerability as Felt		
Worrying	3.22 / 6.41	I worry about..
Preoccupied	38.31	it does play on my mind
Feeling insecure	7.1	sort of feel insecure
Overthinking	23.43	me overthinking these
Terrified	12.36	I was terrified
Shock	21.31	it was quite a shock
Panic	8.8	kind of a panic feeling
Scared	7.45	I found that quite scary actually
Overwhelmed	21.22	it was bewildering
Actively Dealing with it (psychological)		
Breaking it down, step by step	5.1	One foot in front of the other
Self-belief	5.12	a belief you have to keep going
Tenacity: keeping going	27.18	pick myself up & I would just carry on
Using humour: usher moments	11.31	better at laughing at them
Seeing impairment as inconvenience	31.9	it's very inconvenient… the worst thing
Having sense of achievement	2.7/4.48/51	proud of what / could have gone under
Exceeding expectations of self and others	27.15	might surprise yourself
Not making a fuss	5.31	I didn't make a fuss about it
Performing as other	8.44	I can't be that deafblind person
Perceiving & presenting self as 'just like others'	28.43	that's possible for anybody
Seeing vulnerability as inevitable	5.27	inevitably there is going to be a sense
Limiting 'Why do I have this?' thinking	11.16	not too much of that
Learning from experiences of vulnerability	7.47	it's a learning curve
Taking responsibility for maintaining contact	48.3 / 28.6	make an effort initially / network
Actively Dealing with it		
Taking time out: pausing the 'dealing with'	36.3	a breathing space
Demonstrating competence and capability	2.19 / 14.22	I was completely supporting him
Presenting as competent	1.49	doing… a good service
Avoiding avoidance: hitting head on	16.46 / 6.17	how bad can it get? / take things face
Needing bravery	53.13	Been a bit braver then
Looking after and out for self	11.13	Have to look after yourself
Continuous adaptation and compensation	10.30 / 24.25	All the time / compensate
Increasing caution	43.18	much more careful
Slowing down	46.9 / 46.30	have to slow down

Importance of human interaction	27.47	friends are important
Self risk management	46.23	run into something… it's not worth it
Willingness to engage in services	49.21 / 50.41	fancy getting a dog at some stage
Telling others to educate and explain	32.9 / 40.25 32.17 / 32.31	sort of comes up, because of the driving/ if I was gonna be clumsy
Avoiding vulnerability		
Denying vulnerability	5.24 / 14.3	A word that I… shelved / a bit in denial
Avoiding feeling vulnerable	5.28 / 6.13	to avoid feeling vulnerable / stopped
Taking the 'easier path'	4.32 / 5.28	done some U turns / taken an easier
Being overcautious	53.14	Over worry, over think things
Avoiding situations perceived as too hard	40.37 / 13.41	try not to get into those situations
Justifying avoidance	13.47	it's not surprising
Regretting avoidance	52.43 / 5.28	Yeah, that was bad / I've been naughty
Missed opportunities	14.1	I missed out
Valued Support		
Being understood	17.19	gosh, she, she's got it
Needs being recognised and understood	17.19	she knows what I'm up against
Recognising capability	48.29	'well good for you'
Recognition of invisible impairments	37.7	it is visible when you look for it
Not taking over	42.16	not sort… latching themselves on to me
Being looked out for	42.17 / 9.6	just got one eye on me / fantastic
Importance of knowing needs	33.13 / 17.26	they seem to know what to point out
Kindness of others	48.21 / 1.40	nice people / really kind to me
Instinctive help	17.20 /17.7	don't know how she picked it up
Relationships as supporting understanding	17.25 / 31.34	know me quite well / get to know me
Shared experience as understandings	16.26	nice to know that someone understands
Barriers to effective support		
The insufficiency of telling	8.49	they don't take on…
Limitations of aids and adaptations	24.44	don't think that's… keep me going
Aids (visual) as unhelpful	8.45	would struggle… white stick
Declining support: perceived lack of understanding of others	40.19 8.38	because people won't understand that they wouldn't be able to understand
Ambivalence about ageing		
Negative perceptions of old age		
Old age as needing to be looked after	19.43-45	Look after your home
Perceived future difficulties	2.46 / 20.1	getting old will be hard/ not an easy…
Loss of independence inevitable	14.45-47	I guess that's what happens
Reduced life opportunities	24.5	a full life…when younger
Ageing as something feared	2.49	yes, getting old is, is scary

Ageing as loss	2.44	lose you mobility… lose your..
Positive perceptions of old age		
Ageing as an opportunity	2.49	it's a kind of opportunity
Od age as a turning point	3.3 / 6.16	a wake up call / change the way you..
Ageing as a time of reflection	3.14	time to contemplate
Gaining direction in old age	3.4	consider what you want from life
Increased hardship with ageing		
What I'm up against	9.7	What I'm up against
Accelerated ageing: feeling too young for	20.22 / 47.39	old before my time / too young to stop
Increasingly difficult	10.43	it's just, just harder
Difficulties closing in	18.18	closing in on you…
A growing series of challenges	18.16	sort of growing
Ageing complicates deafblindness	2.42	I've got that on top as well
Struggle to compensate	31.15	rely, they compromise, compensate
Reduced independence	15.29	I can just, just manage that
Impact of increased hardship		
Having to be on top form	11.12	Have to be on top form all the time
Concentrating all the time, every time	10.30 / 10.20	have to look out all the time
Feeling stress not vulnerability	10.31 / 10.10	it's more stress you feel
Ongoing stress	10.32	day to day basis
Stress as wearing	35.34 / 24.26	does take it out of you / wearing
Practical challenges as stressors	10.43-47	it's just harder
Before knowing		
Not knowing diagnosis as easier	52.4	better that I didn't know
Not knowing as freedom	51.49 / 53.42	would have stopped me doing… a lot
Diagnosis: the impact of knowing		
Positives of knowing	30.28 / 5.47	good to have a name / wasn't imagining
Changing behaviours	5.48	shouldn't be doing / I changed my job
Making it real	53.47	once you know you've got it, it's there
Needing to know	46.46	you want to know all about it
Initial Period After knowing		
Fear of future	48.33	frightening because you look ahead
Overwhelming	53.21	it just felt too much for me
When it all came apart	5.30	all came apart with the sight…
Ambivalence about knowing	52.8	quite glad…although…

Ageing with deafblindness: a series of benchmarks		
New experiences as benchmarks	45.33	lines in the sand.. that's a new thing
Onset of RP	5.39 / 30.21	problems when reached my late teens
Awareness that it's happening	40.33	oh yes, it's happening now
Impact of sight loss	30.49	sight loss started to impinge
Increased impact of sight loss	44.13	affect me a bit more in day time
Increased awareness of sight loss	10.17	not a time when I'm not a aware of it
Falling over a person the first time	45.16	first time that has happened to me
Unknown timing of benchmarks	37.23	don't know when it's gonna happen
Further adaptation when benchmarks reached	45.31	I've gotta be a bit more careful now
Negative emotional response to benchmarks	45.46	I'm not happy about it
Perceived future benchmarks	54.48	whether that comes later, I'm sure it
Stopping work as terminal	3.48	I'm gonna run out
Ageing with deafblindness: transition and change		
Transition from young to old person	20.26	I was, I'm still quite young
Becoming old	20.24	I've already reached that
Deaf to deafblind	31.23 / 30.29	now… I see them very much together
Physical changes in vision	30.48	sight loss started to impinge
Deteriorating sight loss	10.16	the peripheral vision… got worse,
Changing view of vulnerability	23.7	I view vulnerability differently
Early retirement (ambivalence)	3.47	I'm going to be stopped working…
Continuous change	6.21	Everything's changing, people changing
Ageing with deafblindness: strange process		
A weird process	18.12	quite a weird process I'm going through
Sight loss as a weird process	40.31	
Struggling to understand self	40.19	find it a bit weird
Understanding as process	14.41	I didn't understand…had to learn
Needing direction	53.2	didn't understand at the time wish I'd had… A figurehead
Perceptions of self		
Comparing self to others	23.10	I would be least likely…
Self as different to others	3.47	Most people stop working because of..
Self as incomplete	2.13	a bit missing
Self as wrong	5.39	something wasn't right
Being awkward and clumsy	40.38 / 16.38	I am bumbly sometimes / awkward
Self as resilient	2.4	quite a, a resilient person
Self as deaf	30.26	I was just a deaf person
Self as strong	5.3	I'm quite strong in that respect

Social significance of work		
Work as social fulfilment Work as human contact Work environment enabling human interaction	3.33 3.38 3.29	how would I get social fulfilment how I meet people have to make contact with other people
Telling others		
Sequence of impairment, sequence of telling Telling in stages Telling and shared experience Telling and ongoing relationships Ask then tell	31.27 9.1 / 31.32 34.17 / 34.8 31.34 / 34.2 32.15	that seems to come second Sort of feed them, bit by bit / all in one experience in their lives / so do I have to get to know me / never see they ask… then I tell them

Participant Matthew: Table of Super-Ordinate Themes & Themes

Themes	Page/Line	Key Words
Felt vulnerability as multi-faceted		
Feeling vulnerable as difficult to describe	11.27	don't know really [long pause]
Levels of vulnerability	75.18	all are… vulnerable, to a certain extent
Vulnerable to and vulnerable when	51.17/65.22	its not nice / both to be honest
Vulnerability expected but not experienced (being alone in unknown places)	36.2 / 57.12	it hasn't happened… wrong place / No I haven't
Felt vulnerability informed by the experiences of others	4.44 / 8.8 68.37	know some people who have / seen it happen and I've heard it happen
Felt vulnerability informed by past experience	58.9	yeah, and I've not got [help]
Very early experiences of hospitalisation	10.37/63.24	first three and half years of my life
Experience of ongoing medical interventions	15.15/16.23 20.4 / 49.49	some of the tests… have to have an ECG regular eye, err, field tests…
Vulnerability as time limited, and setting and situation specific: vulnerable *when*	39.44	It wasn't bad, but when I… left
Feeling frightened in specific situations	11.5	I find it a frightening place
Feeling vulnerable outdoors	11.35	as soon as you get outside
Vulnerable when crossing roads	11.33	crossing roads
Vulnerable if alone at night	74.6	night on own…no
Feeling vulnerable in health settings	10.28	when I go into hospital
Fear as all encompassing in hospital	11.10	it's a frightening place… everything
Vulnerable *to* specific harms		
Vulnerable to specific danger in specific setting	60.2/ 60.11	sharp knives everywhere/burn every
Being out alone at night as dangerous	74.12	too dangerous… yeah, too dangerous
Identifying specific dangers	74.20	cars, people, buildings, animals
Being taken advantage of	9.9	being taken advantage of
Vulnerable when and to: support unavailable		
Support needed to keep safe	77.22	Getting me to and from places safely
Ineffective or unavailable support	29.16 / 30.18	go without home care /aren't any here
Support as unsuitable	49.33	not quite what I want
Appropriate support as non-existent	49.39	because A,B and C doesn't exist
Right help from right people unavailable	75.36	the right people aren't always there
Formal support as unavailable	28.45/ 58.30	no home care…available/ don't...help
Support unavailable as ages	61.15	now I don't have that assistance
Requests for support unmet (formal and informal)	57.40 58.9	I'm not sure I'm gonna get it half the time / I've not got it
Negative experience with social services	58.26	Social services… a pain in the…
Unavailability of formal support rendering dependent on parents	90.4	my parents…because of the way the system works in this part of the world
Parents' decisions impacting on own situation	86.25/87.26	here…cos dad had…/ if parents decide

Vulnerability as increased dependency	75.14/75.31	because…need more help
Limited network of support	8.37	because I've only got this friend
No problems if support available	35.43	as long as I've got my parents, I'm fine
Vulnerable to support becoming unavailable	22.6-10	coming up to the age where… I really
Concern about availability and nature of future support	89.49	worried…parents… do a lot for me.. I'd like a guide… you can't have one
Fear of unavailability of desired support in future	59.8	in this climate, I don't think I'm gonna get help for doing…
Availability of appropriate support unexpected	28.35/77.17	practically finished/ would be like wow
Ageing parents reducing available future support	88.2	not sure how long…with his driving
Fear of reducing social life (support no longer available)	65.38 65.48	we don't have many 'get togethers'… / I need a pick up… places out of town
Fear of future lost network of support	22.1	'cos my parents are getting older
Vulnerable when and to: social settings		
Desiring meaningful connection	9.4	a cheque… what do I want this for?
Social encounters with other deafblind people as negative	31.12	Not pretty… break your heart really… It's, it's not great
Negative encounters with other disabled people	31.30 / 32.3	arrogant and obnoxious / it was… bad
No contact with disability groups	31.24	Don't have contact with other disabled
Being left alone in social settings	51.12	and I'm left there on my own
Being left behind, being left out	51.26	me standing on my own half the time
Difficulties identifying people	52.44	that person's here, you can talk
Difficulty engaging with social groups	51.25	everybody… decided to part
Difficulties initiating conversation	52.37	Oh there's X, Y and Z, we'll talk
Difficulties with social activity as impairment related	51.2	difficult because of my sight and hearing
Being different and standing out	51.7	stick out like a sore thumb
Vulnerable to isolation	8.37	Isolation is half of it
Risk of much reduced social life	66.28/67.5	only my, me and my best friend
Fearing further isolation	27.5	it might come one day
Fear of being left behind	4.27/65.27	it's the survival of the fittest
Feeling Vulnerable when: ontological insecurity		
Having a daily routine	37.37/ 62.17	I've got… I lock the house…I check
The unexpected as problematic	61.47	bit of a pain in the neck
Unplanned change as difficult	57.2	that's not easy… do a diverted route
Vulnerable when routine disrupted	62.1/63.13	What? Bloody hell / was doing alright
Vulnerable when others change routine	63.2	When some doink decides… Oh no
Losing control when change in routine	62.16	I don't like getting out of a routine
Being unable to respond to unexpected change	62.1/63.42	I can't do that/ What am I gonna do?
Change in routine as necessitating support	57.6	need a bit of help with that
Routine as maintaining control	80.44	works out well
Routine as enabling to 'keep going'	80.48	continuing…probably

Routine enabling to withstand	62.36	already planned… do the same thing
Sense of self as static	19.31	don't think I'll change now
Continuing sense of self	33.2	over the years… just been me
Ageing as unchanging self	19.10	I haven't changed since I was 20
Fearing the unknown	13.44	cos I have no idea
Change in known environment over time creates dependence	15.13 / 55.23	hospital's changed a lot since / changed gymnasiums..
Difficulty mobilising in unknown places	55.18	not the easiest places to get round
Needing support in unknown places	15.6	dad was going…that's fine
Vulnerability not felt in known places	12.9 / 13.25	in my house, fine / I knew where I was
Awareness of situation as enabling to withstand	20.40	as long as I know what I'm getting' into
Maintaining control in known environments	12.20 37.10 / 59.18	own space… way you wanna do things /I know… layout…it's not a problem
Vulnerable when: unable to withstand		
Ability to withstand as key to vulnerability	75.22	overcome it better than others
Difficulty withstanding challenge	27.37	not strong… holding my own
Feeling unable to cope/manage	63.43	What am I gonna do, how am I gonna
Limited reserves to withstand	8.37	I've only got this friend… & my parents
Feeling unable to cope: losing control	8.39	only got…don't even live in same county
Having less reserves to withstand in future	8.45	lives…miles away… don't communicate
Difficulties gaining employment: less reserves	86.19	didn't leave me a job
Dependence on others to protect	6.20	I rely on my parents or this friend
Deafblindness not only impact on ability to withstand	75.23	linked to how people are made, not everybody's made the same way
Being in control negating felt vulnerability	12.20	do things the way you wanna do things
Felt Vulnerability dependent on the responses of others		
Difficulties owing to the actions of others	73.20	Some… not even bother looking
Actions of others as hostile	7.35	they just mow you down
A hostile environment	4.31	a lot of aggro and aggressiveness
Negative perceptions of others	70.10	'cos you're a beeeep
Negative perceptions of others increasing with age	49.22	get older…it gets worse and worse
Sense of being 'othered'	54.33	we are on class, you are another
Failure of others to adapt communication	13.46	don't talk very loudly
Effectiveness of support dependent on others' actions	72.31	some….care drivers are brilliant… some go straight across
Effective of aids/equipment dependent on others' responses	7.28/71.38	doesn't make any difference/ forget it
Being treated as a 'normal' person	18.15-26/67	treat me like a normal person/ a person
The responses of others: (mis)understanding		
Lack of understanding, awareness & knowledge	71.39	They don't wanna know / stupid

Misunderstanding of others	51.34	they've got it all wrong
Misunderstanding of needs	57.26	come on, you wanna cross the road
Lack of understanding (in presence of aid)	7.45	they don't know what they're doing
Misunderstanding of meaning of aid	71.43	they're stupid
Lack of understanding even from specialist support	91.33	but they just weren't very bright
Own experience of misunderstanding	6.46	I didn't know what it was
Others differing view of risk	24.42	Worse than what I think it is
Experiencing undesired unrequested help	24.40/57.24	grabs hold of my arm/ come on
Experiencing overprotection	24.42	makes it look worse
Needing someone who understands needs	14.25 / 20.16	know what the problem is /he knows
Support effective only if others understand	28.7 / 28.23	does help if the person../makes… easier
Vulnerability not felt when understood	3.39	she knows how to cope with
Shared understanding of disability as positive	32.17/49.18	that's how I felt /same kind of problems
Known and being known	14.39 / 20.13	know them & they know how I operate
Needing appropriate support as a *unique* deafblind person	50.15	not every thing's gonna suit the same person
Vulnerability lessened when known	14.13-19.45	known for years… it's not a problem
Potential of awareness raising	72.25	make a difference… should do
The responses of others: perception of (in)capability		
Vulnerable to perception of incapability	69.45	Oh God, him… he can't do all that
Being seen as incapable if needing support	4.27	it's the survival of the fittest
Being seen as incapable: increasing with age	49.23	Older…it get's worse…Oh he's not good
Fear of being dismissed	8.8	walk past… I've seen it happen
Being overlooked or ignored	9.10	won't even answer me back
Being unrecognised as having something to say	9.20-1	talking to someone…walked off
Being considered as less than	8.4/70.5	has a disability, walk past them like
Being laughed at	69.27	I get laughed at
Early experience of being patronised	85.4	Good boy, pat him on the head
Feeling disrespected	71.39	Walk all over you
Seen as less than vs. portrayed as brilliant	53.30	Oh you do brilliantly well
Self as capable not brilliant	53.30	Yeah, I do alright
Disabled people overstating their abilities	32.20/ 53.11	the greatest, I'm brilliant… they're not
Overplaying of others impacting on capable self	53.22-32	doesn't fit my bill at all / don't like it
Positive recognition by others	17.3	Good report…I'm the fittest person
Support as being recognised as capable	27.46	yes, we can do X, Y and Z
Desired support recognises as capable & enables	68.25	some like that… Yes, we can do this
Recognised by parents as capable	84.29	mum reckons…good intelligence
Vulnerable About: Future as Unknown		
Fearing an unknown future (unable to plan)	65.26	don't know when you're gonna be
Immediate future unknown	81.6	life can throw at you next week
Later life as unknown	78.45	I don't know… No

Further sensory changes as unknown	19.35	It might, but you just don't know
Stability of hearing and vision unknown	79.2	you're still gonna have your sight, your
Maintenance of functional hearing and vision unknown	79.32	I'm not sure how long that's gonna last.. I'm not sure…
Future physical fitness unknown	43.45	not sure how long that's going last
A continuing social life as unknown	65.28	how long your social life is gonna last
Impact of ageing on parents unknown	88.7	not sure how long that's gonna last
Experience of 'old age' unknown	44.2	dunno yet, I haven't got there
Vulnerability as *felt*		
Vulnerability as a reaction to certain circumstances	49.11	how I react to things and why I react… the way I do
Questioning emotions	8.19	Does that seem reasonable or not?
Managing emotions	9.39	I don't always show it
Feeling panic	63.14	Oh beeeeeeeeeep!
Feeling annoyed	8.14/9.14/51	a bit cross / Annoyed/ I get annoyed
Feeling upset	51.45/ 70.22	it's not nice/ a bit upsetting at times
Feeling embarrassed	69.32	embarrassing that is
Feeling uncomfortable	10.38	never been very comfortable
Feeling worried	13.31/62.12	get a bit worried/ worries me a lot
Feeling lost, without direction	11.21	What do I do? I don't know
Physical impact of vulnerability	10.43 / 12.39 16.19 / 62.6	I can get very tight / go…a bit cold / my pulse rate is…sky high / I sweat
Coping: Using Informal Support		
Support with social activity	3.41/52.13	she takes me out / go…with the parents
Informal support to meet others	54.11	where I can talk to other people
Parents as main source of support	3.36	parents… help me with various
Parental support across domains	62.10/67.44	dad, I've got a problem / everything
Informal support with travel	24.29/35.12	*we* do the park and ride/ been to…
Support with domestic tasks	3.35 /29.26	they do shopping/mum does… ironing
Aids, Equipment and Technology as helpful		
Use of equipment & internet to support hobbies	33.34/42.41	does help / use when…I go play bowls
Hearing aids as positive	5.34 / 45.28	it's brilliant / it was like, Wow!
Using equipment for mobility	6.27	I've got a white stick… its got red
Accessing training for aids	7.6	taught me to use that
Positive impact of improved technology	5.45 / 17.31	They're better…I can hear /brilliant
Specialist and mainstream	17.27/33.21	I've got… over the ear ones/ Internet
Advance in technology as improving later life	79.33	best hearing aids in… the universe… lot
The positives of current support		
Current support as relational	61.25	they know me…well…so we talk
Parents supporting the building of reserves	84.16	they were quite resourceful
Support from parents 'as and when required'	3.36	do other bits and pieces… that I need

Support with *shared* hobbies and interests	43.21	and dad has as well
Parents enabling a *full* life	35.8-43	*We* did…been to Spain… Malta… NZ
Support removes or manages risk: looking out for	6.23 / 36.36 68.24	safer that way/ they look around for all….hazards/ looks out for me
Support enabling to enjoy not just do	36.41/ 60.22f	I bounce along… happily/ high cooking
Support makes things easier	1.42 / 13.22	that's quite good / so that's fine
Current support does not negate autonomy	15.7/ 27.47	I'll walk with him/we can do/ good idea
Making own decisions about support	42.29	I'd rather have it
Support maintains capable self	55.42/76.20	make sure I was doing…correct things
Going beyond routine: support makes spontaneity possible	76.6 13.7	might not normally go… a bit different have to think about these things… first
Support enables to withstand	68.22	she sticks up for me because she knows
Ongoing Difficulty accessing suitable support		
Accessing formal support as burdensome	19.17/ 49.37	things I can't get / not always easy to
Accessing support as a battle	90.18	fight your corner
Having to play the game to access support	29.20	gotta play the game… play the ball
Formal support not offered	30.35	was not offered…just wasn't there
Financial barriers	29.6 / 30.24	old adage, money / hole in their budget
Barrier to support: funding other priorities	29.15	had to make a choice
Self as less in need than others	29.11/30.48	more able than most/ disabled than I
Excessive paperwork	92.31	fill in so many damn forms
What helps actually hinders	42.14/51.7	crap… awful… / cos I carry my… stick
Some equipment as limited	41.20	No it's not brilliant
Increasing range of equipment as problematic	50.15	there's so many about…
Experiencing poor quality support	91.18	not been very good
Desired Future Support		
Future support as welcome	58.46/69.23	If I could get the help / that'd be alright
Seeking to secure available future support	27.14	Finding someone…the main one
Having a preferred type of support	22.9 / 58.46	someone who knows what I want
The right help from the right people	76.44	if that right person comes in…
Desired support as ongoing not one off	68.47	sort of a general maintenance
Support 'as and when' required	77.26	general help when necessary
Desired support maintains competence & capable self	75.49	helping… normal routine
Desired support as relational	69.18/92.6	someone of my age/ don't want… robot
Wanting to be 'looked after'	27.10/68.30	Someone who would look after me
Desired support enables doing something new	68.30/76.6	We can do this, that and the other
Desired support as enabling not rescuing	68.47	not… batman type
Desiring someone on my side: standing up for me	27.42/68.24	Someone…to stick up for me / look out for me
Desired support to withstand challenge	68.36/68.42	if I'm in trouble… get me out of scrapes

Coping: Seeking to manage things not change them		
Accepting the way things are	2.47 / 11.22	it’s the way it is…fine / I just have to
Accepting impairment	11.29-37	sight & hearing, but that’s the way it is
Acceptance of one’s ‘lot’ as no alternative	21.44	you’ve got to take life… as it comes
Withdrawing from the world: switching off	11.19 / 13.27	I just switch off / shut out… the world
Psychologically withdrawing as effective	17.12/17.31	shut out… world, cool / no problem
Avoiding negative thoughts	13.38/79.8	I don’t think about that/ Not a lot
Distracting self	9.27	got on with some…stuff
Not taking self too seriously	32.36	don’t take myself too seriously
Letting things go	9.31	Doesn’t always [stay with me]
Taking people as they come	21.38	I take people as they arrive
Just getting on with it	56.36	I can get on with it
Just keep going	80.21	I just carry on… life still carries on
Making best use of residual hearing & vision	13.33	make the best of it
Mixing communication methods	2.17	screen size up… also a voice control
Having a sense of humour	15.35-43 29.49-30.5	It’s like Monty Python’s dead parrot Underpants…Whoops!
Coping: Taking Care of Self		
Having an active life	33.47/35.16	been to a game/been… three times
Self as responsible for maintaining health	17.2	I get a good report
Keeping active, keeping healthy	1.29	for fitness training
Maintaining activities into later life	43.17	playing for over twenty plus years
Taking actions to protect self	37.38	check the garage, fine… check the house
Self risk assessment & risk management	25.15/37.37	so I don’t fall off / lock the house up
Recognising self as at risk	38.24	I had to have done because…my sight
Own risk management: avoiding activities	39.11/60.35	if I leave now / I don’t do the carrots
Managing risk with equipment	38.15	alarm thing… which is good
Taking action: reporting concerns to others	51.39	I told the…person who organised it
Talking things through	26.8	she and I can just talk about it
Building reserves from earlier practical learning	85.45	learnt… practical bits…did help
Making life look good	3.12	try and make life look good
Small things as helpful & making life good	3.23/67.20	listening to my music/ like me sports
Identifying own solutions & coping strategies	6.23/25.2	and it works / call a signalling pattern
Engaging in problem-solving	55.39	two or three test walks
Using equipment in own way	7.6/70.45	I use that, not the way they taught
Own strategies different to professional advice	7.13	I just hold it, at an angle
Maintaining control doing what works best for self	7.19	I’ve always done it and it works
Asking for support	57.20	I’ve always asked for help
Demonstrating Capability to Challenge Others	69.45	Oh yeah… I’ll do all that
Seeing self as capable	3.17/ 26.23	get everything… right / I can sort it
Demonstrating skills	29.26/56.5	do the washing/good sense of direction

Demonstrating self as competent	25.34	I have done…on my own
Self as physically fit	18.31 / 30.47	I'm a fit person / the fitter members
Self as normal, 'just' deafblind	18.32	I'm basically normal, even though I've got a sight and hearing problem
Coping by Getting used to: limited		
Getting used to: new environments	56.36	Alright. I can get on with it
Getting used to using equipment	41.34	Eventually you get it right
Problems reduced when gets used to	21.23 /24.39	most of my adult life anyway…
Tasks easier once used to	25.20	used to getting on… it's not a problem
Getting used to reducing vulnerability	37.12	several times… I know virtually all…
Coping as difficult: doesn't get any easier	67.25	is not easy… its' not easy
Planning Ahead (in practice) vs. taking things as they come (in attitude)		
Making plans for the future	22.15/25.44	talked about it quite a lot / a plan
Needing to plan ahead and prepare	1.39 / 13.7	test walks before / think through first
Planning enabling to withstand	11.36 / 13.8	gotta do this, gotta do that / before I do
Planning for a future without parents	22.39	You have to… mum's side… didn't live
Planning as problem-solving	22.24/66.16	summit meeting…to try and solve
Maintaining control by planning	26.23/ 63.1	I can sort it / I've got that all organised
Avoiding thinking ahead	3.7	I don't… think that far ahead
Taking each challenge in turn	88.27	Cross that bridge when we get there
Taking life as it comes	3.7	take life as it arrives
Taking life as it comes as helpful	10.10/ 33.7	it can [help] / Yeah, it does [help]
Long-standing acceptance of life as it comes	9.36 / 32.40	it's the way I'm made/ ever since school
Sensory Impairments as Separate		
Being registered blind	1.47	registered as blind… since 1978
Focus on sight loss / visual impairment	36.14/52.43	for being blind / another pair of eyes
Self as blind	29.16	for blind people
Having hearing loss and sight loss	11.34 / 38.24	my sight and hearing
Changing Levels of Impairment		
Deterioration owing to additional conditions	5.1/79.21	I've lost one eye / I've had nystagmus
Expecting further sensory loss	13.33-39	it won't last forever/ as long as I… keep
Experiencing significant change in vision	79.20	changed quite a lot over the years
Additional sight loss problematic	5.6	that didn't help much
Positive changes in vision	79.22	internal cataracts…were removed
Period of stability in vision	5.22	fairly stable since
Experiencing change in hearing	5.30	noticed a bit of changes
Hearing improvement owing to medical intervention	5.33 79.46	best things I've ever had / hearing better now than… any time of my life
Changing use of aids	5.31	been through four or five hearing aids

Changes as requiring adjustment & intervention	55.29/56.14	had to have a complete tour round
Regular sensory tests as normalised	19.49	I've *only* had four hearing tests since..
Cause of Difficulties as multi-faceted		
Hearing loss alone as unproblematic	6.7	don't hear everything, not a problem
Impact of environment not impairment	73.18/73.41	so I can at least see both sides
Being unable to compensate as multi-faceted	13.46/74.32	don't talk very loudly/ got more light
Risk of reduced social life multi-faceted	67.6	they could all move out of town
Deafblindness exacerbating existing difficulties	50.24	never easy even if… you have full sight
Experiencing deafblindness	73.28	My eyesight's not brilliant at night
	6.18	people running around everywhere
Ambivalence about ageing & old age		
Ageing as unproblematic	48.16	I don't have a problem with that
Ageing: just another year on	48.11	another year on, to tag on to my life
Ageing unnoticed and not thought about	2.44 / 4.18	haven't thought about it / dunno really
Age as 'just a number'	2.47	it's just a number
Perception of life expectancy unaffected by deafblindness	78.19	I've got most of my dad's genes
Living into later life as positive	78.4/78.33	if I'm fortunate / 90 if I'm lucky
Ageing as an equaliser	19.5/ 70.28	everybody gets older/end up being
Experiencing & expecting increasing difficulties	6.16 / 67.1	used to go / future… not gonna be easy
Life getting harder	4.26/ 49.30	got…a lot harder/ like a minefield
Life as a series of challenges	81.6	what life can throw at you
Possible physical decline in later life	43.46	body's going to last
Additional health conditions	1.29	have a heart defect
Expecting to need more support as ages	22.6-10	coming up to the age where…
Expecting isolation as ages	22.8	could do with someone to talk to me…
Expecting to receive support in much later life	59.9	until just before I leave this world

Participant Phillip: Table of Super-Ordinate Themes & Themes

Themes	Page/Line	Key Words
Vulnerability is multi-layered		
Ways of being and feeling vulnerable	11.6/ 12.1	one way of being, of feeling vulnerable
Aspects of vulnerability	12.35	mobility aspect of vulnerability
Different areas of vulnerability	10.32/12.30	All sorts / is in lots of different areas
Vulnerable to and vulnerable when	10.42/12.2	temporary bus stops/ over hanging branches
General feeling of vulnerability as cumulative		
Felt vulnerability as cumulative	12.24/19.31	all contribute to my general feeling
Previous experiences influencing future felt vulnerabilities	10.42 17.27	have taken away the temporary bus stops/ until something awful happened
Vulnerability about	37.22	sleepwalking into disaster
Feeling vulnerable 'when' informing feeling vulnerable 'about'	23.3	very difficult for me to talk about this
Being and feeling vulnerable as different	49.11	on that occasion he actually took me to
Vulnerability felt emotionally	17.17/23.17	feel really vulnerable / emotional
Felt vulnerability influenced by stories of others' experiences	50.32	Absolutely. It was mentioned on the radio as well
Felt vulnerability informed by others' experiences	12.13	A man in… he got knocked down by a car
Feeling threatened	15.33/52.30	Threatened/ go back… feel threatened
Feeling intimidated	16.28/ 30.48	Started… feel a bit queasy/ intimidation
Feeling lost	18.32/19.31	I don't know what to do
Felt vulnerability changing behaviour	50.1	I don't do that anymore… Now I rely
Avoiding situations where felt vulnerable	50.24	Once bitten, twice shy
Vulnerable to: Vulnerability to specific outcomes		
Vulnerable to different outcomes	10.32	All sorts of things… All sorts of things
Vulnerable to potential negative outcomes	49.11	fuck knows where… I was gonna end up
Identifying self as at risk of harm	7.9	Heck health and safety as well
Vulnerability to physical harms	7.8/ 12.2	Straight into a beam, an overhanging
Vulnerability to being attacked	10.36	being attacked in the street
Feeling vulnerable to being hate crime victim	50.28	yes, a victim of crime. Disability hate.
Unrequested help	10.36/49.1	man trying to assist/ grabbed my arms
Vulnerable when: Vulnerability setting and situation specific	42.8/48.13	Those kind of situations/ incidents that
Support unavailable	10.41/ 34.32	stupid buses have taken away
Existing support is removed or withdrawn	20.37/ 36.23	they can't, can't take…felt vulnerable
Lacking or losing control	10.22/ 31.8	I don't know whether…/ been forced
Feeling out of control	16.36	I didn't… know what was going on

Availability of support controlled by others	4.7	my line manager was… reluctant
Vulnerable in unknown environments	10.47/48.44	don't know where we are/ frightening
Vulnerable in shared spaces	10.16-22	shared spaces… it was horrible
Being dependent on others	49.3	vulnerable… can you take me to the
The actions of others	16.49	I left the day centre… my hearing… alibi
Being unable to withstand	51.18	I can't… move to another table
Being unable to remove self from situation	51.23	If I could see, I would… other side of the
Being and Feeling Misunderstood		
Perceiving others as misunderstanding	32.6/ 49.15	some idiots / didn't seem to understand
Misunderstanding of needs	15.4/ 20.49	do you need help…question mark!
Misunderstanding of extent of sight loss	12.44/ 27.21	think I can see a lot more than I can
Extent of sight loss perceived as misunderstood	13.6/ 26.6	She thought I could see something
Impairment not recognised	28.8/ 29.15	could you fill out the form…/ pass this
Being disbelieved	29.36/ 40.18	look alright to me/ more than I could
Being misunderstood (even in presence of visual marker)	26.5 27.14/ 30.19	a stick… probably… partially sighted/ had white stick… can you follow me
Others misunderstanding even when told	26.8	when I told her… couldn't grasp the fact
Needs misunderstood even by specialists	27.11	even I'm afraid…here
Professionals perceived as lacking understanding	39.38 40.4	the CPN…the psychiatrist… don't know/ CPN…taxi is here… could you go
Those with same condition misunderstanding extent of sight loss	48.34 49.35	didn't know the extent of my sight loss… / I have actually got worse… than
Expecting others to understand if known	51.3	they know me there…
Explaining misunderstanding		
Usher unrecognised	2.9	6 or 7 years ago
Questioning awareness of Usher	2.1	Have you heard of Usher syndrome?
Late diagnosis	1.46	The final diagnosis is Usher
Ignorance of others	40.29	was an idiot… enough common sense?
Professionals perceived as lacking knowledge	39.39	never seen anyone like you before
Deafblindness as an invisible impairment	45.46	she had no idea… I didn't say I was
Invisibility of RP as disabling	13.15/ 26.12	a hidden thing…double disability
Having different needs to the majority	10.46	you got to the next… no good to me
Difficult for self and others to understand	41.17	For them and me
Outcomes of (mis)understanding		
Needs (at risk of) being unrecognised 28.8	10.10/15.10	don't think about people/ what about
Feeling needs are ignored/overlooked 30.34 32	12.3/ 12.16	don't do anything/ wasn't interested
Frustration of unrecognised needs	30.21/40.6	that made me fuming/ and screamed
Limitations not understood at work	31.42f	I could work…. could not understand
Inaccessible environments	39.46	no white, white lines on the…steps
Environmental accessibility easier to resolve	39.49	was all sorted… got have resources
Lack of understanding resulting in physical harm	32.8	caught my head on the corner… off sick
Having difficulty in health settings	39.28	problems at the mental health hospital
Others perceived as lacking compassion	20.46	not sympathetic to my needs

Others perceived as lacking patience	20.45	I said be patient. Lacks patience
Experiencing the negative perceptions of others	52.13	Bet he's on benefits… he manages… well
Policy as lacking understanding	30.38	progressive… yet… got to be reassessed
Misunderstanding expected	41.38	Yeah, yes, *of course*
Offered help as recognised need	13.8	I didn't know…would you like… help
LA recognising needs	4.26	due, due to my needs
Being understood valued	22.31	Thank you for understanding
Being known, being understood	27.9/ 27.41	my bank knows me... they would know
Level to which known impacting on level of understanding	27.10	know me fairly well, they would… kinda know that I can't see
Being understood by services	27.41	she knows me & got used to me quickly
Support wonderful when needs understood	51.47	helps me… he will do that… wonderful
Mixed Responses to Feeling Misunderstood	26.17	depending on how I feel
A desire to be understood	47.18	Please understand me
Seeking recognition of needs	7.4/ 7.13	how can I?/ who's going to get the food
An ongoing need to tell and explain	28.35/ 49.36	have to keep on explaining/ explaining
Informing and explaining to others	21.6/23.17	sent… loads of information/ if you read
Having to tell (to explain behaviour)	29.22	It's something I have to do
Using aids to tell others	27.20/ 28.19	then I shook my stick… he realised
Aids as confirming impairment	1.22	I use two powerful hearing aids
Having explain as annoying	29.24	I get very annoyed
Having to explain as frustrating	40.32	I can't see… freaked out
Explaining and telling as wearing	26.19/ 29.23	Tired and headachy
A desire to be heard	40.32/58.30	screamed loud/like to have a word..
Desire for voice to be heard unrealised	49.14/59.28	I shouted and screamed/ weren't allowed to speak
Needing Recognition of Self as Capable		
Demonstrating self as capable	5.36/ 15.46	had articles… published/ran a… class
Demonstrating self as talented and skilled	17.30/19.23	I compose music… I played at/ I play
Recognition of capability highly valued	46.45	immenseful…meant ten times more
Being valued and appreciated	18.2/19.40	they loved it. People came up to me
Recognition and value as 'life support'	20.37	life support system… pulled the plug
Supporting others: self as contributor	15.41/17.38	work at a day centre… ran… workshop
Valuing making use of existing talents and skills	46.36	purpose… when I started playing again
Demonstrating competence at work	32.2/ 32.44	onto a database/ able to… important
Lost recognition of capability feared	47.22	I was losing that job…I was worried
Desire to be recognised as more than deafblind	18.3/19.25	please… tell the manager/ since I was 5
Being 'deafblind' as reduced identity	45.18	inverted commas deafblind…
Fear of reduced identity	45.48/47.5	I didn't say I was deafblind
Playing the deafblind card reducing identity	46.6-47.5	deafblind card… want to be an equal
Being recognised as capable reducing felt vulnerability	20.4-11	keeps me…back to… how do you cope
Self as capable unrecognised	16.10	why do we need… a service user to run
Challenging negative perceptions of self as needy	47.9/ 58.32	don't want.. I'm deafblind, I need help
Needing to be needed	19.2/ 21.38	staff started to light/ I need people to

Job as sense of purpose	19.8/19.49	It gives me a sense of purpose
Ambivalence about Ending Work		
Difficulties at work	31.48/36.11	all sorts of problems I've had
Having limitations at work	31.42	work adequately… had limitations
Work highlighting limitations	33.13	I couldn't cover… I couldn't do that
Struggling at work	3.47	I was struggling
Ending work as a relief	3.34	Well sort of relieved in the end
Taking early retirements forced/undesired	31.15/ 35.31	I was forced out… medical retirement
Old Age as a discrete, chronologically defined life stage		
Old age not reached	8.17	I don't think old is until
I'm not old yet	9.40	I haven't reached that age yet
Changed perception of when old age is reached	10.11/10.20	living a bit longer/ I thought 75… rather
Old age as unknown	9.40	I don't really know
Getting older unthought-of	9.23	it's not something that I, I think about
Transitioning between young and old	9.48	middle, err, err, senior middle aged
Pension as part of transition	10.3	I'm not pensionable age
An Unstable Identity		
Sensory Impairments as separate	1.17/ 7.25-9	I'm deaf and I'm blind
Focus on sight loss	4.12/ 12.43	my eyesight/ deafblind… I can't see
Identifying as 'blind'	40.6	I'm blind, I'm blind
Identifying as 'deafblind'	12.43/20.47	deafblind person/ like myself
Identification of self as impaired	48.22	I'm the worst one… got it very badly
Deteriorating vision as deteriorating self	4.12	I was slowly deteriorating, my eyesight
Self as deteriorating	5.6/ 26.9	I now suffer/ I *was* actually a lot worse
Self as different to others	33.2	not expected to stay… I stayed
Comparing impairment with others	48.21	his eyesight's much better than mine
Difficulties multi-faceted	14.19 30.16	couldn't walk…chairs and tables/ doesn't speak up very much
Ageing as ongoing adaptation and adjustment		
Ongoing need for adaptations	8.18/ 33.11	Getting older? … having to readjust
Changing needs due to deterioration	38.31	now I'm having difficulty [to] read
Deterioration in vision	38.25/48.38	the time… eyesight faded/ to go bad
Ongoing changes in circumstances	8.18	different changing circumstances
Adapting to changing circumstances	8.40	instead of having… have it delivered
Adapting to changed circumstances: other health problems	8.34	accident… might not be able to do…
Changing environment necessitating adaptation	53.40	route needs change.. moved the Post
Minor but ongoing changes	8.45	minor things at the moment
Adaptations at work	32.20	post was fairly well adapted
Changing technology requiring adaptation	4.16/ 4.45	technology, it couldn't keep up/ the old

Unpredictable changes, immediate adaptation	9.18	unpredictable… have to make changes
Financial implications of adapting	9.9	I have to make funds available for it
Reducing activities	8.35	not be able to do rowing once a week
Adapting activities to render accessible	56.25	because I can't walk… use my exercise
Adaptation as two way	33.10	they had to adapt and I had to adapt
Change and adaptation as inevitable	9.14	it's just one of those things
Ongoing and Increasing Difficulties	8.19	It's very difficult… very difficult
Benchmarks in deterioration	38.32	progressing beyond a certain point
Reaching benchmarks: increased dependence	4.2	in the end I had to rely on… Access to
Deterioration marked reduced functional use	38.25	could not look at…screen any more
Focusing on extent of sight loss	26.7/ 27.21	It's more like severely sight impaired
Focusing on extent of hearing loss	7.33	I don't hear properly
Difficulty mobilising and accessing buildings	7.17/ 14.21	the loo and back?/ difficult to get round
Difficulties if alone	7.4/ 9.8	I can't go… on my own, how can I?
Difficulties in unfamiliar environments	14.41-5	OK…familiar…unfamiliar… hopeless
Difficulties associated with sight loss	48.29	got it very badly… couldn't really walk
Impact of environment on difficulties	30.12	It's very noisy, she talks quite softly
Lacking awareness about immediate environment	7.37 20.40/ 44.39	Where has the cat settled, do you know? didn't know the volume level
Additional health concerns	4.41/5.1	the effects of eletro-hypersensitivity
Additional health problems complicating deafblindness	37.9	can't have… vibrating pillow…electricity
Deafblindness complicating additional health conditions	39.28	problems at… mental health hospital… didn't understand… my eyesight
Difficulties affecting mental well-being	35.21	I cracked up, I couldn't cope
Impact of deterioration on mental health	35.30/38.33	Finally collapsed, nervous and sheer
Cumulative effect of difficulties	36.12	Just the last straw [holds head in hands]
Experiencing ongoing battles and conflicts	21.2	I had to fight a case
Feeling threatened	15.33/16.41	yes… Threatened/ feels threatened now
Feeling under attack	16.9	decided to attack me in different
Feeling rejected and unwanted	18.23-8	we don't want… I felt so… saddened
Cumulative effect of impairment, experiences and lack of recognition of needs	41.9	petrified. It was like suddenly I'd gone blind… I was shaking
Winning a battle	44.20	seem to have cracked it
Having someone on my side	16.19/ 21.6	nodded his head, supporting me
Having people on my side	18.33/20.31	I've got… on the case/ they went up to
Law is on my side	12.20	It's against the byelaws
Taking responsibility for own well-being		
Engaging in training	14.36	I have had long cane training
Willingness to engage in future training	53.38	I ring up my… rehab worker
Learning new skills	55.19	I've learnt them over a period of time
Taking own remedial action	12.8	I have to go round… cut them down
Making complaints, raising concerns	10.49/ 12.3	I've complained… to the RNIB/ council

Proposing own solutions	11.28/ 40.43	The solution is / could have asked… me
Own problem-solving	6.10/ 8.40	we use a code and put it on the paper
Protecting self	44.33/45.35	so it doesn't happen again/ in writing
Remaining in control	6.6	I decide to do, decide what action
Use of support not negating autonomy	43.28/53.33	I agreed to anyway/ I sign the cheques
Building own resilience	56.8	Otherwise… I'd… cracked up long ago
Looking after self to extend life	10.12	choose a lifestyle which is healthier
Lifestyle choices impacting on old age	10.16	reduce the years rather than increase
Engaging in activities to enable self to withstand	55.1-3	can reassert my body… I have control
The small things	56.30-8	stroking my cat… a cup of coffee.. small
Slowing down, doing less	8.23	I am… having to slow down… not do quite so much
Psychological Coping		
Mental well-being activities reducing felt vulnerability	17.22/55.40	practising… meditation helps/ It helps. It helps
Acceptance	9.8	I've resigned to it
Demonstrating self as autonomous	6.6	I decide…what action
Moving on and letting go	41.26-31	Long time ago… chapter that's closed
Engaging in positive thinking	56.39-43	appreciating / weigh up your positives
Perseverance: keeping going	57.7	I try, yeah.
Accessing and Using Care and Support		
Offered help wonderful and welcome	13.9/14.15	I'd love some help/ it's wonderful
Support from others welcome	51.28-47	who always helps me, the lovely... man
Entitlement to support	4.25	entitles me to, to various serv…
Support with mobility	4.3	and [pause] car there and back
Supporting with social life	6.26	As part of my leisure
Support with clerical work	6.16	filling out forms…. diary entries
Support with and not for	5.45	personal assistance… we do the
Accessing support to support others	6.26/ 22.15	supporting the community/ give… back
Using financial support	4.2	rely on erm Access to Work
Using LA care and support	4.25	I have a… support, care and support
Accessing help with hearing aids	27.33	change the tubing… wonderful service
Using combined care and support: technology, aids and human assistance	4.31-6 5.31/ 5.45	use headphones… connected to the telephone… a computer assistant at the
Aids alone insufficient	14.36	long cane…But even so
Limitations of equipment	4.16/32.33	it couldn't keep up with my software
Using equipment at work	32.26	an old closed circuit television, which
Needing flexible hours	6.34	level out… have to average out
Engagement in deafblind groups	27.25	at the… In Touch Group
ROVI Training as enabling	54.20	training so I can get there and back
ROVI Training as essential	54.5	100% vital. Vital, essential!
Accessible services valued	27.29	comes over… don't have to go all

Participant Anthony: Table of Super-Ordinate Themes & Themes

Themes	Page/Line	Key Words
Levels and layers of vulnerability		
Different needs, different vulnerabilities	33.42	everyone’s got different vulnerabilities
Vulnerability and iatrogenic risk	38.18	Touching the body gives an image
Response of self and response of others	9.37	accept what’s going on
Felt vulnerability as dependent on own actions	22.6	not vulnerable, because I ask
Felt vulnerability dependent on others’ responses	5.28/ 5.42	My vulnerability depends on my human interaction with people
Vulnerability as neutral vs. vulnerability as negative	31.13/30.35	Well, it’s in-between/ Vulnerability… you’ve given up
Vulnerability as felt		
Worrying	5.2	I get anxious
Being afraid	41.49	I was a little bit scared
Feeling annoyed	24.20	I was quite annoyed
Feeling angry	42.34	I was cross, I was cross, cross
Getting upset	5.22/42.34	sometimes when I’m upset
Feeling low	8.27/9.8	a bit low maybe/ can feel a bit low
Vulnerable when: vulnerability as situation, time & setting specific		
Vulnerability not constantly felt	31.13	I’m vulnerable, but I have a guide…
Situation specific: that relationship, that person	5.42	that relationship, that… person
Vulnerability in social settings	8.6	I’m left on my own
Vulnerability in hospital setting	41.13/42.8	went to hospital/ where’s the support?
Group living as challenging independence	20.34	don’t want to live in a group
Vulnerable when unable to withstand	19.15/30.35	prevent me from thinking of new
Vulnerability as inability to cope	30.44	cope with… vulnerability, hmmm?
Feeling vulnerable in unknown places	21.41/42.27	strange place… I’m vulnerable
Vulnerable when: lacking the full picture	2.24/ 5.10	he hadn’t told me/ don’t get full picture
Vulnerable when: support unavailable	13.35	I can’t go out… nobody here
Vulnerable when: losing control	36.41	Vulnerability is about control
From not understanding (incapable) to understanding (capable)	1.38/ 1.47	it began to open my mind / it enabled me to…tell them what to do
Between two worlds: restricted (parents) v opened (education, friends)	2.7 2.43/ 3.9	stuck in the middle of two worlds: my parents and social life/ two worlds
Vulnerable when: lacking the full picture	5.18/22.22	That’s vulnerability, that’s a struggle
Deaf to Deafblind: losing the full picture	5.7-13	I don’t know what’s going on
Not being told	3.47/ 4.10	feel low… didn't tell me/ a secret
Vulnerability as narrowed communication	4.44/5.20	communication becomes very narrow
Lacking the full picture: boundaries as confusing	36.1/37.6	public laws… difficult… to understand
Challenging boundaries: is it wrong?	38.4-14	Is it wrong? Did I abuse you?

Lack of information owing to actions of others	55.18	talk behind my back
Lacking information as multi-faceted	41.31/42.4	nurses were changing all of the time
Assertive self depends on having the full picture	30.13	to explain… then I can be assertive
Lack of information: no ability to withstand	31.17/41.35	so I know what I'm doing/ was scared
Lack of information problematises solution finding	22.24	information to… work out how to solve
Needing full picture to understand ageing	16.13/16.40	talk to… about changes/ to explain
Having the full picture as enabling capable self	22.45	I got it wrong… the guide will tell me
Knowledge gives potential	47.34	Knowledge gives potential
Having knowledge enables to accept	4.2	be realistic… accept… eye problem
Needing information on own behaviour	55.23	if I'm being too demanding… tell me
The safety of having the full picture (health)	22.36	pain, I can say can you just check what
Full information keeping self safe	22.2	give me information… to keep me safe
Touch as providing the full picture	37.47	you feel the shoulders, you're laughing
Inconsistency rendering lack of the full picture	42.4/ 60.6	are always changing/ so many changes
Vulnerable when: support unavailable	6.3/21.32	I depend on… / nurse had gone off
Support unavailable: boundaries of role	6.32/24.4	is outside of their boundaries
Support unavailable: others lack of skill	16.37/42.2	don't… know how to use tactile sign
Support unavailable: insufficient hours	42.6	limited hours… two or three
Support unavailable: assumptions of family	43.9	they think… you just have family
Support unavailable: lack of funding	42.20	try & claim back… hours… don't know
Requests for support misunderstood	42.29	nurse didn't understand what I say
Difficulties finding the right support	6.4	difficult to find
Not being supported in the desired way	24.5	No, I like to do it differently
Needing more than 'deafblind services'	44.20	professionals… trained… communicate
Vulnerability and dependence	17.16/22.15	depends on the availability of guides
Enforced dependency creating vulnerability	47.4	that's why I'm vulnerable… new rules
Unavailable support affects spontaneity & choice	6.3/ 6.41	if I want to go out, I can't go/ I can't
Vulnerability not felt when support available	22.34	I feel safe, I feel good
Vulnerable when: losing control & being controlled		
Vulnerability as losing control	36.41	Vulnerability is about control
Control as being told what to do	28.23/29.20	telling me to shhhh… could control me
Vulnerability of being restricted	6.46	you can have sex… but I can't
Vulnerability as not knowing what to do	31.15	means.. doesn't know what to do
Vulnerability as helplessness	30.49	vulnerability… helplessness
Vulnerability as giving up	30.35-31.4	given up… isolation I help myself
Potential of depression to control	8.36	don't want depression to control me
Need for support does not mean needing to be controlled	29.40	It's the same with you… we're all the same… don't like when people control
Self as not vulnerable when in control	31.22	not vulnerable, I know what to do
Isolation: vulnerable when and vulnerable to	4.41-5 19.13-17	Big problem… where a lot of the vulnerability is
Isolation: the highest level of vulnerability	6.1/ 7.48	The base, the highest level
Losing contact with the world	4.47	contact with the world… why I struggle

Human contact to survive	6.10/7.30	want human contact/ I can't survive
Human contact as necessary to build relationships	7.13	build up that contact.. you need that
Human contact as physical contact	7.3	contact, to be able to touch somebody
Physical contact and boundaries as complex	7.36/37.2	get torn between/ crossing the line
Support 'rules' negating human interaction	6.9/6.14/55	their strict rules… I want a human
Human contact needs unmet by guides	25.47-26.14	from a guide you can't have that
Reduced contact with others	4.33	contact with people became less & less
Reducing social life	4.25/17.30	contact I had with my friends got less
Needing help to initiate engagement	27.10	she'll encourage people… sit with me
Communication difficulties when 'just' Deaf	1.24	it was really difficult
Isolation as reduced communication	8.5	hello… spell my name… then they go
Reduced quality of communication	4.31	just a few words… amount… less & less
Communication 'breakdowns'	1.46	communication breakdown
Impact of communication difficulties on family life	1.17/ 1.19	never understood/ very little… poor
Communication with other Deaf as problematic	8.4/8.10	deaf person… then they go off
Communication as difficult for Deaf and Hearing	17.6	Deaf people or hearing… communication can be difficult
Felt vulnerability dependent on others' responses (personal & structural)	25.29	It will depend on the person
Discrimination rendering as vulnerable	46.32/46.44	can't fly/ where's my protection…
Failure to recognise as a human with rights	47.28	deafblind people have human rights
A human with rights, not an object	7.28	I'm not… an object, I'm human
Vulnerable when seen as disabled first	57.18	vulnerable when… disability first
Being seen as less than human	7.28	not like an animal
Professional boundaries creating vulnerability	6.8-12/6.28	their rules… big aspect of vulnerability
Others' character	5.32	different characters… some people
Others' (un)willingness	27.16/27.37	some people are interested in
Unwillingness of Deaf to communicate	8.8	don't want to… want to... just sign
Others' apathy	43.17	they just don't bother
Communicative ability of others	5.29/27.9	depends on their skill or… talent
Failure of others to adapt (communication)	4.26/ 4.35	they felt like it wasn't easy / a burden
Perception of being vulnerable renders me vulnerable	47.22	check with me my knowledge, my safety… Don't misjudge…Ask
Others' fear of human & physical contact	7.49/25.19	frightened of the human contact
Others' fear of communication	4.34/8.1	maybe people felt frightened
Strategies only effective if positive response	43.15 44.48	when you give them to the staff… they don't pass that on../ don't have time to listen
(Mis)understanding: feeling and being (mis)understood		
Own misunderstanding	1.34/2.14	didn't understand/ I never understood
Seeing others as misunderstanding	58.25	so many people misunderstand
Being othered: in a different world	5.6	think I'm living in a different world
Parental misunderstanding	2.27/ 2.35	father… they'll make you blind
Difficulties misunderstood	1.26	didn't realise why I couldn't walk

Being seen as clumsy: misunderstanding	2.12	tell me I was clumsy… I didn't know
Misunderstandings as 'breakdown'	5.13/43.35	breaks terribly/ it's just a breakdown
Not being understood: expressive communication	42.35	didn't understand.. if I'm in pain
Vulnerability of misinterpreted physical contact	7.23/36.19	sexually attracted by/ scared of.. law
Others not knowing how to support	7.49	don't know how to deal with me
Requests for support misunderstood	42.29	nurse didn't understand what I say
Mainstream older people's services as misunderstanding needs	20.13/33.7	they're all Hearing people here / it has to hang… No, it's my mobility, I follow
UK services not having the full picture	44.34	the left eye is not talking to the right
Vulnerable to losing individuality	59.24	individual needs, your individuality
Being understood as an individual	23.20	to understand the person I am
Vulnerability not felt if understood	5.25	she understands me
Explaining Misunderstanding		
Deafness not recognised	1.26/ 1.30	didn't realise I was Deaf/ didn't know
Usher unrecognised: not knowing what's wrong	2.11/2.45	never knew I had Usher/ many years
Homogenising older & deafblind people	33.14/33.34 48.31/59.23	never thought of me as different no criteria to differentiate
Self as different	9.24/9.43	whereas I'm different
Lacking understanding as lack of training	42.48	training the nurses… it's lacking
Limitations of formal training	23.38/24.3	had training… had a different way… no
Expecting & experiencing staff to lack knowledge	45.6/ 60.4	often don't know/ actually don't know
Lack of knowledge not recognised: unconscious incompetence	59.21 60.2	I know… because they're trained/ think they know everything
Lacking awareness of communication needs	43.18	nobody explains the communication
Focusing on impairment not needs	43.19	just say, deafblind patient, that's it
Usher difficult for others to explain	3.44	difficulty… trying to explain..
Understanding deafblindness as insufficient	24.23	[specialist agency]… they don't know
Communication skills alone as insufficient	23.36	have BSL… OK.. not a full answer
'Reading the file' as insufficient	60.17	they look in the file, but they think differently
Expecting to be & being perceived as incapable		
Abilities unrecognised in childhood	2.31	she never said 'well done'
Others' low expectations	1.33/ 2.31	kind of give up hope/ Deaf… she cried
Expecting people to question capability	29.13	you're surprised
Presumed incapability	32.44/57.7	She thinks she's helping. No, I can do it
Others lacking belief in capability	32.45/49.17	You can do it?/ can you… well how?
'Rules' presuming incapability	47.29/47.23	might not be a problem/misjudge... ask
Presumption of incapability causing overprotection	47.14	safety… can't fly on their own
Being seen as incapable	5.33/48.30	people think I can't help/ you can't
Being treated like a child	55.9	off… reporting to your supervisor
Being dismissed as incapable	47.26/48.12	just dismiss me/deafblind can't, can't
Being patronised	56.35/57.34	it's a shame… I hate being patronised
Being undermined	55.8	via your manager… didn't feel very fair
Perception as lacking potential	47.42	don't respect the potential that… have

Moving between worlds: deafness to blindness	4.12	a different world again
Sensory impairments as separate	4.12	blindness…completely different
Deaf world as positive	5.9	offered me a wide world…
Deafness as unproblematic	4.23	Deaf… friends… an active social life
Prognosis a shock	3.42	progressive blindness… was a shock
Becoming blind: focus on sight loss	3.47/4.24	I was going to go blind/ became blind
Losing all sight: a short trauma	4.4	was quite a short trauma
Deaf as identity, blindness as impairment	1.11/ 4.24	I was born Deaf/ blind very different
Sight impairment as 'something wrong'	2.23	something wrong with my eyes
Late Life as Time of Development	21.10	I explore things and experiment
Early life as a struggle	2.42	it was a real struggle
Going beyond life of parents	2.8	friends… world that they have given
Being old as being experienced	15.47	I'm experienced
Being more worldly	2.3	learn about the world
Ongoing potential as ages	51.37/52.8	always moving forward
Learning new skills in later life	19.22	teaching me different things… check your balance on the phone
A complicating interaction: ageing & Deafblindness		
Lacking information on the ageing process	16.40	need… explain what getting old is
Expecting increased need for support as ageing	31.39	I'll have to ask people to support me
Deterioration in vision	4.21	I became fully blind
Bodily changes increasing risk	15.49	getting older. There's lots of risks
Difficulties as more than impairment	17.15	largely that's to do with location
Difficulties as multi-faceted	17.5/ 17.12 19.39	location here is quite far/ far from friends/ when I moved here it was..
Old age: physical change, stability of self		
Old age and physical change: intrinsically linked	32.8	old age and physical change
Old age as physical decline	15.48/16.16	pains within the body/ more tired
Body getting old	15.48	body's changing.. body's getting older
True old age as frailty	16.21/16.26	not old… very active/ true old.. frail
Ageing as increasing frailty	16.22/31.39	used too be much stronger… bit less
Unchanging perspectives as ages	31.49	I've always had the same views
Questioning self as old		
Old age as a discrete stage not yet reached	16.21	I'm not old yet
I'm not young	31.45	I'm not young
Not feeling old	15.47	I don't really feel like I am old
Taking Action to help self: Educating Others	45.29	give them lots and lots of information

Teaching others: the gift of deafblindness	27.36	deafblindness is a gift, I can teach
helping others to know	45.6	explaining how to get attention
Teaching my way: Rejecting ways of formal training	23.43/24.7	to teach… my lifestyle, how to guide *me*
Teaching others to communicate	44.47	I explain about communication
Teaching others to understand	3.18/23.20	help them to understand/ lot of help
Maintaining independence: helping others help me	25.28/40.16	I explain tactile sign/ show it to the
Reducing others fears	5.6/23.21	make people comfortable/ they feel
Willingness to challenge	57.44-47	I will tell them… what I think
Challenging presumed incapability	32.46/49.16	I can do it / are not dummies
Helping others accept my capability	49.9	to accept my capability… I will show
Challenging perception of the self as at risk	39.40	maybe I'm at risk… [laughs]
Demonstrating capability: how I do it	49.19/51.9	I will show you… How… have a look
Sharing information to keep self safe	45.40	tell then to sign S for security
Raising awareness ongoing	45.11/45.46	explaining again and again and again
Raising awareness as tiring	45.10/46.7	takes a lot of energy/ Tired
Taking Action to help self: Learning from Others	5.37	I learn from each person
Learning how to cope	5.1	I learn how to cope
Learning communication	1.37	taught me how to communicate
Learning creative activities from others	18.18	brilliant, it gave me the idea to create
Willingness to ask others	22.6	I'm not vulnerable because I ask
Asking others helps to problem solve	31.33	I ask questions… to sort the problem
Taking action to help self: finding own solutions		
Self as solution focused	9.7	have to think about the solution
Capable of finding own solutions	8.17/ 13.36	I… help to find the best way/ what I do
Being creative to problem solve	17.45	on my own, I have to be quite creative
Keeping occupied	8.30/17.47	just try and keep myself busy
Creativity as two-fold: activities & new strategies	18.5	be creative… think of new things
Creativity as enabling to withstand	19.7/19.46	be creative to escape from the isolation
Creativity: a fulfilled life	18.36	have a fulfilled life.. painting makes me
Art as remedy	53.36	a remedy for me
Artwork as managing emotions	10.42/11.11	express my feelings through… pictures
Using art to make sense of life	10.23/51.31	an expression of my blindness/ my life
Own strategies as effective	18.3	It's kind of the best way
Taking action to help self: Planning and Preparation	45.13-18	Don't have a plan, you get a bit lost…must know how to prepare
Planning & preparation as necessary to withstand	29.9/31.35	I can organise myself/ have to prepare
Planning as maintaining control	28.47	on my own, I just made different plans
Planning prevents problems	22.4	a card that has deafblind manual on it
Coping as planning ahead	28.34/41.14	I'd written down/ Before I went… I
Withstanding as preparing and sharing information	45.6/45.35	prepare and give them information

Making use of reserves		
Using mixed expressive communication	2.2	[starts with ASL] hearing friends
Making use of residual senses	50.37	I can feel it with the string
Using remaining senses and memory	12.16-29	remember… feel them… and imagine
Reminiscing as helpful	9.9/18.1	think about the past, memories
Learning from parents as reserves	3.20/9.10	father did give my a lot of wisdom
Taking own actions to build reserves	19.40	go away… learn new things… build
Learning from others as building reserves	19.17/19.28	new people give me new ideas
Own body as a source of information	32.7	follow your body
Slowing down	32.7	have to slow down
Maintaining control: supported in own way		
Work with own Code of Ethics	26.26	I have a code of ethics
Finding new guides: word of mouth	24.35	existing guides… speaking to other
Use of support not negating capability	50.14	colours I do myself first, I ask…how
Use of support not negating autonomy	24.39/58.16	I'm the employer… I decide everything
Direct Payment as validating capability	25.1-8	feels good, because I feel responsible
Use of Direct Payment as maintaining autonomy	23.19	put my stamp on/ doing it my way
Employing own staff	23.10/24.7	I interview for… ask about their work
Taking action to Maintain Connection		
Managing isolation	13.37	it helps me to feel human contact
Physical contact as curative	7.5	like a medicine
Human contact as connection with the world	7.6	helps me to feel part of the world
Maintaining contact with the Deaf community	21.8	I've visited old Deaf people
Having mixed friendships: Hearing and Deaf	20.28	happy to meet Hearing or Deaf people
World as felt: tactile and tactual	11.43/12.42	feel the expression/ statue of David
The importance of touch	7.4/36.37	physical contact… is very… important
Value of touch: validating self as human	14.2/37.30	it kind of feels like me/ you feel human
Touch as twofold: a full picture & human connection	14.39-45/ 38.40	hold my hand to show…it feels good to have that human contact… short
Using mainstream technology	17.13/19.21	got some friends through 'WhatsApp'
Artwork as connection with others	53.30	it's like engagement with people, I'm not isolated
Supporting me, supporting you: support as mutual		
Supporting others	10.1/28.20	I give them advice and… help them
Desire to help others	3.11/ 3.30	in my heart I wanted to help people
Early experience of helping others	3.3	I had to help my mum a lot
Self as helper and helped	49.1/ 56.4	happy to help / we support each other
Supporting others to manage risk	38.27	I encourage people to touch
Independence as being capable of helping others	48.49/49.8	To be independent you have to think how you can help other people

Adapting and Adjusting		
Ongoing adjustment	4.15	find out… to replace your sight
Adjustment as compensating for loss	7.9/ 50.37	replace what I have lost/ I can feel it
Coping as compensating	17.49	can't… go for a walk…, so I try and
Coping by finding alternatives	5.2/14.17	be altered….try to find… an alternative
Making own adjustments in interactions	5.38/8.17	social interaction that I adjust, I adjust
Coping strategies as time limited	19.47	bit tired of the same things
Others need to adapt and adjust	5.44/17.10	they have to calm down and… adjust/ forget about communicating with me
No practical solution? Coping as psychological	8.44	no solution, so why feel that way
Positive thinking as coping	4.7/4.9/9.7	was positive, I suppose/ think positive
Avoiding 'why me' thinking	10.4	not the only one with bad experiences
Coping by distraction: avoiding rumination	8.28/8.36	I'll do a hobby/ put it out of my mind
Acceptance of self as is	32.8/33.22	accept.. I'm not superman!/ who I am
Understanding and acceptance of self	10.18	understand myself
Accepting what cannot be changed	9.2/32.5	accepted… going blind/ getting old
Accepting life's ups and downs	4.37/10.34	don't have regrets/beautiful & struggle
Failure to accept as leading to anger & bitterness	9.34/10.2	they feel very angry so bitter and angry
Support in accepting deafblindness	5.19	people who help me accept
Withstanding by changing how feels	9.38/19.46	what's the point in being angry
Withstanding by changing response	19.30	not lonely… to be happy alone
Same difficulties, responding differently	9.46/59.4	I'm the same… but I forgave him
Using humour	34.40/40.2	I'm joking/can't really see you [laughs]
Rejecting pity	27.35	don't want them to feel sorry for me
Remaining relaxed	9.28/9.37	I'm much more relaxed/ kept calm
Managing own emotions	8.28	try and pull myself up a bit
Empathy and understanding of others	3.25/17.19	had his own weakness/ have their own
Empathising with others' responses	4.36/ 8.15	I understand that / I understand why
Not apportioning blame	4.42/8.16	I don't blame them.. it's not from them
Understanding others as imperfect: forgiving	3.33/10.5	accept what people have… forgiveness
Understanding others' difficulties	10.5	many people have different problems
Letting go by accepting the limitations of others	3.32	be more human… everyone's not perfect
Standing up for Self		
Self as strong willed	5.43/33.5	I'm a strong willed person/ tough
Being assertive	2.39/5.22	fight for myself/ mind of my own
Independence as asserting rights	48.5	assertive… to tell you… my rights
Taking action to prevent being controlled	28.27/29.17	No, it's my decision… you can go
Rejecting being told what to do	23.42/57.35	don't tell me what to do/ I know what's best for me
Making complaints, protecting self	47.13	I've written a complaint

Effective support: available, understood, the full picture		
Effective support available ‘as and when’	23.14/27.8	availability/ isn’t with me… if I need to
Effective support necessitates deep understanding	6.6/24.23	need to understand the depth of my
Effective social work necessitates being known	60.17	they get your background
Effective social work as consistency	60.16/60.49	it’s OK, if I get the same one
Staffing knowing how to help: fantastic	44.32	fantastic… they know how to help you
Guides providing the full picture	16.36/22.47	my guide… she can explain things
Needing a multi-disciplinary network	43.43	work together… a network of…
Effective support: a professional and a human	11.19/56.2	she’s a professional… a human… both
Effective support as relational and experienced	6.14/11.10	be able to relate/ it’s beautiful
Effective support as relationships: knowing, matching, working as a team	5.26/20.47 23.17/23.24	we’re compatible, we’re harmonised/ matches what I like/ we get on
Support from someone on the same level	5.39/6.10	relationship on the same level/ share
Desiring human support	6.7	just like professional… want a human
Support relationship as developmental	24.22/55.14	feedback… improve the… relationship
Effective support as beyond job roles	43.4	not enough to just give… tablets
Task focused support neglecting relationship	6.29	that’s just business… my relationship, my feelings

Participant Rose: Table of Super-Ordinate Themes & Themes

Themes	Page/Line	Key Words
Vulnerability experienced as time limited and situation specific		
Vulnerability not felt as constant	30.45 / 79.15	Occur to me when I'm out / little things
Infrequency of feeling vulnerable	26.48 / 29.35	very few things / hasn't happened
Denying vulnerability	26.28	Don't want to use the word
Risk as setting specific	21.16 / 21.35	the simple one is / example of
Early experience influencing feeling of being at risk	24.40 / 44.18 45.21 / 46.10	memory… still horrifies me
Interaction of age, deafblindness and situation	7.45	that came into it as well
People at the door	21.17	somebody comes to the door
Being unable to recognise others	21.22/ 27.18	I don't recognise people / recognising
Crossing roads	30.8	Not happy crossing roads
Being unable to communicate	72.29	Anybody wants to talk to me
Being at risk of trips and falls	29.37	trip over a paving stone
Being at a disadvantage	8.22 / 9.34	Somebody… always going to be ahead
Being treated less favourably	60.6	not worth bothering about
Being in unknown places	16.42/17.20	A strange building/ never been…
Being outdoors without hearing aids	72.28	More vulnerable
Inability to hear others responses	21.31 / 38.8	can't hear what they say
Being own company not a major concern	96.33-38	my own company *too much*
Feeling lost	5.46/6.22	so little guidance / not told what to do
Understanding of Vulnerability		
Vulnerability as being in danger	21.10	Could be in danger
Vulnerability as being at risk	21.5	some element of risk
Vulnerability of others as inherent	57.4	vulnerable because… health problems
Social Interaction as setting for felt vulnerability	31.36	My interaction with other people
Awkward social interactions	27.48-28.19	wasn't anything funny
Being with unknown people	17.1	people that I didn't really know
Being unknown to others	31.42	they don't know you
Difficulty making friends	9.21-22/32.34	to be bothered with it / only make
Difficulty joining and being in group discussions	14.21 / 31.41	I can't join in / a small group
Difficulties with eye contact	32.4 / 51.13	Don't get eye contact
Fear of offending others	27.33 / 28.32	they'd be offended / hurt or offend
Fear of being seen as unfriendly or unsociable	27.34	think I was unfriendly, unsocial
Missing out	8.31 / 14.20	wouldn't do things / I miss out
Being ignored or rejected	3.22 / 43.32	particular school wouldn't have me
Feeling of exclusion	52.34 / 65.11	I just feel… I still miss out a lot
Being excluded	14.21 / 32.8	I can't join in / you're excluded
Enjoying the company of others	96.28	I do like company

Need for support as setting for felt vulnerability		
Dependency on others	17.24	Couldn't have managed without
Required support unavailable	2.13/24 / 6.1	prevent my getting the right help
Not wanting to ask for help	17.34	otherwise I would have had to ask her
Mixed responses to requests for help	18.8 / 20.24	depends on situation / not going to
Requested support declined	19.49 / 37.21	I didn't get it
Ineffective support	19.37	not really very helpful
Constructed dependency	51.19	nobody did make me aware of it
Needing guidance	51.12	nobody told me
Feeling frustrated	20.40/ 37.21	frustrated
Needing additional help in later life	15.48 / 73.39	I do need help with certain things
Inability to respond to threat as felt vulnerability		
Dependence on others to protect self	9.36	wouldn't…on my own
Being unable to respond	24.29 / 32.8	what could I do / until you can make
Feeling unable to protect self	8.23	can't run away
Self as less able to withstand or respond to threat	82.40 / 87.28	younger…more able to take the knocks you get / less able to cope with it now
Responding to Risk		
Self risk assessment & risk management	8.46 / 29.16	it wasn't worth it /possibility
Being more cautious	87.32-47	more to be aware of
Faith as support, security and protection	29.31 / 29.47	helps me… my faith / pray for safety
Avoiding overthinking	30.44	don't sit and ponder
Withdrawing or taking time out	65.17	to get away…get away from everybody
Fear as motivator	10.14	desperation, fear
Asking for help if needed	18.4 / 19.33	can ask for help when I need it
Felt safety with support	30.16	gives me a feeling of safety
Avoiding vulnerability	82.32	I'd feel too vulnerable now
Vulnerable to negative perceptions of others		
Early concern about the perceptions of others	46.1/10	As children of course…/ rubbed off on
Felt an embarrassment to father	45.21/ 54.13	An embarrassment to my dad
Questioning the perceptions of others	11.19	don't know whether more evident
Questioning impact of ageing on perceptions of others	35.13	It's difficult to know
Perceptions of others unknown	40.15	I don't know how
Avoidance of stigma	12.46	quite a lot of stigma
Being seen as stupid	32.11 / 51.27	just left standing / that I am stupid
Feeling at risk of being seen as stupid	31.27 / 59.47	people think… I'm very stupid
Perceived as incompetent	7.35 / 43.38	like an adolescent / up to much
Perceived as more needy	9.42 / 11.21	overprotective / being more needy
Seen by others as 'a liability'	3.42	too big a liability to them

Exposing weakness in others	15.26 / 46.32	aware of their own weaknesses
Responses of others to disability	15.23 / 28	people… can't cope with disability
Increased feeling with age: a has been	58.34	weaker… 'has-beens'
Being disregarded or dismissed	58.33	not worth bothering about
Being seen as unworthy	59.26	really not worth bothering about
Negative self-perception	15.40 / 39.47	I don't shine in anything
Full acceptance as unachievable	15.22	it never will be a hundred per cent
Feeling most vulnerable if misunderstood	81.8 / 81.21	Went on a lot of time / most
Risk of & being misunderstood	51.23/31	Not sure aware / felt misunderstood
Feeling misunderstood	1.47 / 54.9	my parents thought… in their wisdom
Questioning how well others understood	52.18	how many people really understood
Misunderstanding of impairment	65.27 / 79.38	me
Impairment unrecognised by family	67.20	didn't realise couldn't hear/don't really
Fear of needs being misunderstood (even if asked)	17.45	own family didn't recognise it worried… in case… didn't understand
Needs misunderstood (in presence of visual marker)	37.23	Go and look at the board
Meaning of aids misunderstood by others	37.16	
Well-intentioned misunderstanding	2.4	don't seem to know or understand
Ignorance of others	37.48 / 79.34	thought they were doing it for the best
Impatience of others	38.9 / 38.16	downright ignorant/ they don't realise
Presuming others will know	65.32	wasn't grasping quickly enough
Expecting better of health care staff	7.24 / 81.4	people would know by now
Health care staff lacking understanding	7.17	like children themselves/ knew better
Invisibility of deafblindness in services	12.35	just had no understanding hearing or sight problems
Disbelieving as misunderstanding	7.45 / 80.31	
Being disbelieved	6.6/8.2/ 79.45	thought I could hear / didn't even look
Feeling that not believed	43.32 / 81.22	made it all up /suspicious
Being caught out (proved wrong)	7.19 / 80.5,37	nobody believes me
Questioning the necessity of equipment	72.8	do things to try and catch me out
Ambivalence about the cane: security v perceived need	36.44	doesn't seem necessary well do I really need it
Vulnerability to being exploited		
Exploitation	87.24	the whole thing of being taken
Fear of exploitation / being taken advantage of	21.12 / 28.37	Frightened of being taken advantage of
Being taken of advantage of as exposing limitations	25.36 / 26.29 59.38	Didn't know they were doing/ made me aware of my weakness
Being scapegoated	9.17	everybody accused me
Being deceived	24.24/28	felt there was something wrong
Increased awareness of exploitation risk as ages	21.11 / 29.11	more aware of it now
Being horrified	21.35 / 24.40	awful / horrifies me
Feeling upset and angry	24.33 / 25.42	really very upset / really cross
Feeling uneasy	24.31	still very uneasy

Challenging the misunderstanding of others		
Being assertive	10.9	courage to say that
Making and asserting own decisions	46.20 / 61.2	Make my own decisions / I don't want
Challenging the perceptions of others: proving them wrong	10.31-2	prove that… they were right
Demonstrating capability and usefulness	4.4/10.46	my autobiography
Proving capability: a life long struggle	10.36	struggle with me all my life
Exceeding expectations	10.9	don't know how I even had the courage
Presenting self as like others	5.23 / 12.4	mother… as well
Challenging overprotection as a turning point	9.44-8/10.22	making it more difficult for me
Vulnerability facilitating growth	10.30	I managed to keep alive
Performing as more impaired	81.46	pretend I didn't see it
Knowing and being known well	6.43 / 21.27	know them well enough
Telling others: challenging by telling	38.11/ 38.22	I don't think you've treated me very
Perception of self as competent	40.2	a certain amount of understanding
Self as supporter of others	22.33 / 22.46	helped at a homeless project
Telling others		
Telling others to explain & educate	18.45/27.23	I tell them why/ bear in / 80.32
Coming out to others	14.46	being more open about it
Telling to educate as own responsibility	66.38	as I *should* be
Telling as required	27.29	the only way
Getting used to telling	14.34	It doesn't bother me now
Increased willingness to tell as ages	14.26 / 14.35	Not afraid to tell people / was a time
Willingness to use symbol cane now	35.38 / 36.30	A symbol cane / confirming disabled
Becoming acceptable to tell	14.30	more acceptable now
Responses of others to telling	14.39 / 69.38	does make a difference
Insufficiency of telling	65.40 / 66.1	a bit different / up to a point
A changing response to being misunderstood as one ages		
Changing attitudes, increased acceptance	12.47 / 14.30	now…much more acceptable
Changing perception of others over time	44.20 / 54.45	was more about me than he realised
Reduced stigma (over time)	14.37	stigma… isn't so evident now
Recognition that others may not know	81.36	not everyone would know
No apportion of blame: did their best	2.29/3.18	did the best they could/school
Difficulties understanding self	52.33	as an adult… I began to understand
Improved awareness of others over time	37.38	they are getting better
Increased willingness to tell	14.26 / 14.35	Not afraid to tell / was a time
Attributes of valued support		
Being recognised as having potential	73.25/31/94.1	it was recognised… amazing/chance
Recognition as capable and competent	62.39	treated me as a colleague
Being understood	27.22 / 32.46	Some people understand / get to know
Being treated like others	63.10	the same way as me

Instinctive and spontaneous help	17.8-14/25	automatically did it / just done it
Feeling respected	32.44/ 62.45	given me respect / respect
Own decision in own time	76.3 / 92.23	I decided / my decision… not theirs
Someone to ‘fill the gaps’	73.32 / 73.43	fill in all the gaps for me
Being and feeling accepted	6.37/41/14.39	know and accepted / never held it
Being accepted as full self	36.27	don’t mind using white stick… here
Importance of friendships	9.25 / 22.28	close, erm, loyal friends
Ineffective Support		
Limitations of aids and equipment	36.43/76.13-7	On the other hand
Limited effectiveness of aids	37.6 / 75.39	Not always… it doesn’t work/ problem
Insufficiency of telling	65.40 / 66.1	a bit different / up to a point
Problems with technology	14.27	problems… with sound system
Guide dogs as restricting freedom	93.37	restricts your freedom
Ambivalence about the Future		
Concern about future ability to manage and cope	73.9	how would I manage
Fear about future coping (experienced in youth)	9.48 / 10.15	how am I going to manage?
Future as daunting	73.8 / 74.7	A daunting thought
Fear of future reduced mobility	30.36	mobility outside more difficult
Expecting future deterioration: not that bad yet	68.19 / 72.48	isn’t *yet* / I sense that it possibly will
Loss of coping strategies	16.1	when younger… can cover up
Fear of future hearing loss	30.35	fear losing my hearing completely
Unconcerned about the future	31.27	not something daily burdened with
Future as unknown and uncontrollable	31.6 / 68.23 91.45 / 92.6	futures don’t work out / could come / haven’t got any ultimate control
Ambivalent about planning for the future	31.6 / 68.14	can’t plan for future / yes and no
Preparation not planning: future proofing	68.48 / 71.18	I know deafblind manual / if I need to
Avoiding thinking about future deterioration	73.3	try not to think too much about what
Ageing as blending in vs. continuing to stand out	11.21/35.16	I seem to stand out.
Early awareness of difference	2.6 / 3.8	older than my peers
Always the ‘odd one out’ in the family	46.46/ 47.1	odd one out in the family / still so
Treated differently to sibling	3.22	school wouldn’t have me
Being marked out as different to peers	3.7 /11.39	because of my age, being older / not all
Being ‘othered’	78.12	that all other children were able to do
Seeing self as different	2.6 / 2.16	older than my peers/sort of borderline
Humiliation and embarrassment	3.7	I was so embarrassed and humiliated
Avoiding being different	94.37	It’s less conspicuous
Avoiding attention	36.15 / 94.37	Going to get even more attention
Declining aids to avoid attention	36.23	If you put the red on as well
Symbol cane as a visual marker	35.25	I do use my white stick

Old age as levelling	34.21 / 34.29	Regardless of disability/doesn’t matter
“two merge into one”: deafblindness and ageing as inseparable	35.13 / 58.28	Merge into one / fairly general
No longer the odd one out	13.19 / 14.7	now my sister doesn’t hear very well
Peers acquiring impairment in later life	64.6	most of my friends… have a disability
Shared experience: blending in	33.29 / 34.25	just as I have moved / true for anybody
Shared experiences of disability	66.8	sometimes she feels quite frustrated
Shared vulnerability as better relationships	54.35-38	he was able to understand me better
Questioning shared vulnerability	55.37	I just don’t know
Blending in as solidarity	14.29	they complain about it as well
Reduced identity: little old lady	39.14 / 63.42	another little old lady
Disguising and Denial: earlier in life, ending in old age		
Early experiences of disguising and denial	67.10	was a time when I ..bluff my way
Disguising and denial of hearing loss	13.13	I had to… disguise.. I couldn’t hear
Disguising by bluffing	13.14	I bluffed a lot. I made guesses
Denial of impairment by others	11.29 / 11.12	my father didn’t want to accept…
Family disguising of impairment	12.37 / 46.19	dad was shutting her up / don’t tell
Disguising influenced by family	67.28	difficult for me to do anything else
An end to disguising in old age	13.18 / 13.44	It’s different now
‘Getting used to it’ as limited		
Mixed acceptance	74.16	Accept it on one level… not too easy
Acceptance of impairment	14.19	Well I accept it
Accepting ‘my lot’	78.23 / 92.10	Just accept it / whatever my lot is
Getting used to it as coping	19.27	if I couldn’t cope with that now
Getting used to as familiarity	78.42	used to in the sense its familiar
Not getting used to it emotionally	32.16	still find it very hurtful
Early experiences as painful	3.46-47	never forgotten that / really hurt me
Not getting used to it (exclusion)	78.46	haven’t got used to…just as painful
Hoping to be able to accept the future	92.1	content in whatever… happens to me
Changing perception in age as supporting acceptance	78.37-38	another word you could change it from
Changing perceptions: self no longer the problem	3.33	I realise now that’s what it was
Late life as time of growth and development		
Desire for growth and development	49.8 / 83.30	Started going to bowls / stretch myself
An active life	48.31-45	Volunteering / on their access group
Acquiring new skills in later life	49.14 / 71.13	Need much more practice / learnt that
Engagement in training in later life	48.27	gone to a few little courses
Additional future training as welcome	95.26,37	asking for retraining / would welcome
Willingness to use alternative communication	68.14 / 69.6	could…use audio
Using aids in later life	35.25-30	20 years ago I wouldn’t have done
Being useful and a desire to remain useful	47.42 / 90.41	little bit of voluntary work / useful life

Using public services	19.26 / 19.33	use public transport all my life
Willingness to engage in future care services	96.15	if it was needed yeah
Not feeling old	63.49	I don't feel it
Experiencing rather than being deafblind		
Deafblindness as incidental to experience	5.1 / 39.9	nothing to do with sight and hearing
One impairment as more evident: situation specific	11.31 40.49	hearing hidden… couldn't deny sight more evident than the other… example
Environmental impact	18.30 / 53.23	if the rain's in my face /where standing
Focusing on each separate impairment	30.35/ 48.13	fear of losing my hearing
Deafblindness as unique impairment	66.47 67.4	most / harder to do when got both
One impairment hinges on the other	50.31	one hinges on the other
Difficulty in compensating	21.31 / 50.34	can't hear what they say / can't depend
Questioning impact of deafblindness	33.11	how much of that due to my disability?
Deafblindness as a non-stable impairment		
Deterioration in hearing as aged	16.7	my hearing has gone down
Mixed pattern of deteriorating vision	16.21 / 74.22	to a limited degree
Additional sight condition	5.4	about 30, I had a detached retina
Hearing aids in middle age	12.5	didn't get until my early 30s
Changes in hearing aids	71.28	had these…about 18 months
Impact of deteriorating hearing	72.43	wasn't always so, but it is so now
Increased awareness of VI & HI as aged	11.18 / 11.28	sight & hearing more evident
Changes in medical knowledge and intervention over time	5.35	medical knowledge has moved on
Deafblindness as incurable	75.8	nothing they can do about that
Deafblindness as complicating other health problems	6.49	don't go well together
Impact of reduced information in early life	51.13	no one ever told me
Little guidance on managing health	5.46	so little guidance
Missing out on information	59.16	she didn't tell me where
Additional health problems in middle adulthood	5.10	discovered that I was diabetic
Being unable to manage own health	6.24	ended up with anorexia
Additional health problems in later life	58.45	had a hysterectomy
Accepting difficulties as part of ageing with deafblindness		
Difficulties in childhood	1.49/2.6/ 2.37	Didn't go to school until I was six
Life as a series of ups and downs	26.43 / 41.34	they're just life / ups and downs
Living one day at a time	31.2 / 31.15	day at a time / very much day to day
Facing difficulties as and when	31.22	meet it when I come to it
Keeping up, keeping going: tenacity	6.48 / 10.38	one way or another, I've coped
Because you 'have to'	30.21 / 30.29	I've had to / example
Small ongoing difficulties	26.42 / 38.7	little things are happening

Incidents ongoing but unremarkable	26.43/ 27.13	don't even think about / 27.6 mundane
Increased difficulty over time	51.6 / 73.39	wouldn't have been necessary…is now
Loss in old age as inevitable	34.33	It's just part of life
Not making a fuss	62.11 / 62.38	I wouldn't want…fuss about it/big issue
Low expectations of equipment	77.21	never get anything perfect
Actively Managing		
Own problem solving	20.30 / 30.12	trying, exploring around / crossings
Seeking own resolution	24.38	we had a meeting the three of us
Making use of residual hearing and vision	30.34	look and listen as best I can
Future proofing self: having reserves	10.20/ 68.46	had the foresight / alternatives
Adapting communication methods	68.28 / 69.36	technology has changed it
Using aids & equipment	16.36/ 47.33	I do wear a hat thing / a pager
Using technology	68.37	Use of email
Sense of vocation	23.36/45	part of my ministry / meant to be doing
Old Age as a Time of Reflection		
Seeing things in a new light	4.9 / 53.48	Seen… bad things… in a different light
Reflection as catharsis	4.27	good for me
Working through experiences	4.28 / 55.35	working through all that/ thinking it
Reflections informed by the experiences of others	51.36	I have been reading a book
Having no regrets	41.35	I don't regret it
Facing early experiences unwillingly	4.44	not very keen

Participant Caroline: Table of Super-Ordinate Themes & Themes

Themes	Page/Line	Key Words
Questioning Vulnerability: understanding vs. feeling	15.26 30.18	Ask… what you meant… I'm not sure I think it's all in my head
Understanding informed by what heard	22.40	You hear terrible tales
Early experience informing future vulnerabilities	16.32/16.42 55.10/55.25	that's happened when/ from that point I can still remember their names
Vulnerability understood as linked to inherent characteristics	16.8	less physically strong…hearing or sight… worse
Vulnerability understood as universal	23.34	I think everybody's vulnerable
Reduced identity as vulnerability	25.4/35.2	blind old woman/ sum total of my eyes
Distinguishing between feeling vulnerable and feeling at risk	15.28 16.17/23.16	a distinction between vulnerable and at risk/ do feel at risk… but not vulnerable
Experiencing people as helpful despite fears	29.42	they're… more likely to be helpful
Specific outcomes: at risk of		
Feeling at risk: being attacked or a victim of crime	15.18 16.23/16.46	threaten you… attack you/being attacked…grabbing my bag
Feeling at risk: attracting unwanted help	16.22/20.7	being done good to/walking me across
Experiencing unrequested and unwanted help	16.36	grabbed me… thought I'd help
Fearing future sight loss	4.48/20.43	I can't have that, I'll go blind/ worry me
Fear of further or total sensory loss	20.31-43	would rather die before I lose my…
Concern about future ability to cope	21.5	it would be very hard to deal with
Personal injury as feared outcome	17.11	of personal injury I suppose
Felt vulnerability and felt risk as time, setting and situation specific	23.39 60.37	vulnerable as circumstances make only thing…. made me feel vulnerable
Vulnerability not felt as constant	15.34/ 17.31	don't feel that… but it could come/ only
Self as not vulnerable at present	15.40/16.17	feel vulnerable… not yet/at the moment
Not feeling vulnerable to attack or abuse	17.24/30.13	I don't feel vulnerable
Increased felt vulnerability as age	16.8	in about 15, 20 years, I would
Felt risk not constant	16.17	I do feel at risk *sometimes*
Feeling at risk when alone	17.7/19.5	feel more at risk if I'm on my own
Feeling at risk when home alone	16.44	on my own here at home
Being unaware of danger	16.46	not knowing if the fire alarm goes off
Situation as lessening the impact	5.13	was no need…went in same direction
Environment increasing impact	7.7/ 9.41 35.28	don't know anybody in this area… don't know the lay out/ wasn't much traffic/uneven pavements
Feeling vulnerable when net effect is lost control	20.11 42.35	horrible thought… can't control your worse nightmare
Vulnerability as losing control	16.12/20.3	less in control of what was happening
Vulnerability as being controlled by others	15.32/20.7	somebody… take me over

Experiencing lack of control	19.3	have absolutely no control then
Vulnerability as cognitive incapacity	15.48/20.12	might not know/ don't have… capacity
Total loss of sight and hearing as loss of control	17.33	don't really know what's going on
Being out of control in unknown environments	19.9/50.9	not knowing where I was/ panic
Familiar environments as safe	15.13/49.24	indoors, in a safe familiar surrounding
Desiring control over own life	41.23	want to be in control of my own destiny
Desiring sense of interdependence	22.1	kind of pay back… he needs to be able to go and do his own thing
Being able to withstand : Multi-factored		
Vulnerability as being unable to protect self	15.33	powerless to stop them
Vulnerability not felt if feel able to withstand	23.4	don't think I'd be vulnerable
Having mental capacity as ability to protect self	23.9	have.. capacity… good awareness
Being able to protect self	16.39	No, get out of my space!
Lacking ability to withstand	8.21/10.39	would be more able to hold my own
Lacking reserves to withstand	6.38/9.8	unless you've got ready built circle
Situation impacting on ability to build reserves in earlier life	6.43/25.42 53.5	was working or… dealing with children/ I had… memories there
Lacking reserves and resources to cope	8.16/19.14	I can't get out/ nobody to go out with
Increasing DSI impacting on ability to withstand in later life	26.7	good, you can take up old hobbies, I can't do those
Cost of support as prohibitive	22.10	but expensive… it's means tested… I'm not prepared to use up all our savings to pay… too expensive
Maintaining control		
Own decision making	2.29	I decided to go for
Making own decisions about support	1.36/18.43	which I wouldn't wear/ it's my choice
Own problem solving	2.2/ 2.44	turning my head/ take a torch/ can tell
Own risk assessment & risk management	17.47/19.27	turn lights on / avoid going out at night
Taking control of adjustments	40.41-7/41.8	I decided… I have/ driven by me
Keeping active to avoid cognitive decline	56.24	Keep your mind active…brain active
Using equipment	18.12/45.8	It's useful.. white cane… does help me
Using reserves to fill the gaps	45.31/46.13	got used to…do gap filling/ own reading
Using mixed communication methods	43.8/45.40	use other communication methods
Willingness to use and learn new communication methods	42.27/43.29	Interest me most… hands-on signing… I would be open to it/ would like to learn
Willingness to ask for help	18.30/36.27	Can you give me a hand/ prefer to ask
Accessing Support Increasing felt vulnerability	34.32	actually start to become… vulnerable
Needing human assistance	19.4/19.16	totally have to rely on somebody else
Having difficulty doing things alone	37.14	things I couldn't do… on my own
Accessing support as seeing self as in need of protection	22.35 34.37	start to accept that you need to be looked after and protected
Support as changing perception of self as capable	37.20	lulled into a sense of…. I need help

Highlighting needs as felt vulnerability	34.48	stop thinking about my needs… making to fight… not vulnerable, I can manage
Support contributing to felt loss of independence	34.38/ 34.42	
A gradual erosion of independence	34.37/36.12	it's very insidious/ they've offered
Support as being taken over	22.35	vulnerable… try and take you over
Overthinking as a result of engagement with organisations	21.16	Being involved with them… I'm think about it more now… I'd rather not
Overthinking increasing perception of self as in need	21.22	that I *think* I can't do anymore
Complying with perception of deafblind people as vulnerable and in need	36.17	pandering to the fact that you do have a dual sensory loss
Accepting support offered though felt as unnecessary	36.16	I can do it. But since they've offered… accepting their help
Responding to the concerns of others	50.26	got told… it's bad for you… who's right
Vulnerability to overprotection	20.22-28	Think they know what's best…
Limitations of equipment	18.17/46.49	It's a nuisance… kind of lose one hand
Feeling, Being and Expecting to be misunderstood	23.46	they don't understand
Needs being misunderstood	10.34/16.38	he just mouthed everything/ confused
Lack of recognition of changing needs	39.23	expect them to recognise… don't
Feeling at risk of being misunderstood	16.22	being misunderstood
Expecting misunderstanding	24.1724.22	other people won't see me as that
Expecting disbelief of others	28.21	somebody thinks 'but you can see'
Misunderstanding of others even when told or explained to	3.13/11.1 24.13	I can't see… that's a bit odd/ such a lack of understanding from people
Misunderstanding perceived as ignorance of others	18.20/30.6 54.8	idiotic bloke…. he was stupid/ You moron/ she was a bit ignorant
Misunderstanding by those trained	34.48	I don't need you to do that… stop
Family misunderstanding needs	2.45/19.17	more carrots/not sure my husband…
Lack of understanding as no one's fault	11.1	And it's not their fault
Impairment being misunderstood even in presence of aid	18.25/18.31 24.18	White cane… that curtain pole/ you can't see a thing can you/ you can see!
Declining aids owing to misunderstanding of others	18.34	red bands on white cane… people don't know what it means… no point
Terminology contributing to misunderstanding	24.7/28.3-21	deafblind… but you're not/ doesn't
Defining self differently to avoid misunderstanding	24.22/28.12	so now I would never describe myself as deafblind unless I … had to
Impairment as invisible	9.19/9.22	couldn't see there's any problem
Late recognition of hearing loss	1.22/ 1.42	until I was 5/ wasn't true/ nearly 6
Hearing loss unrecognised	1.21/1.24	nobody realised… hearing problems
Usher not recognised	3.44/5.2	connection was never established
Diagnosis focused on single sense	4.25	viral nerve deafness… didn't connect
Own misunderstanding	3.17	didn't strike me as particularly odd
Comfortable when understood	36.38	Yes… they understand… the nature of it
Questioning own identity	28.22	think to yourself, if… really blind

Vulnerability to misrecognition as incapable as prevailing	29.34	overriding thing… don't want to appear stupid
Being seen as incapable expected, perceived and experienced	8.28/25.4	perceived as not very bright/ probably see me.. bumbling old has been
Risk of being seen as incapable as overriding	7.28/15.8	I can't take the risk that I'll just end up
Bullying as early experience of being perceived as incompetent	54.12/55.9	get bullied… oh yeah… At school/ chanting… Deaf, dumb and damn stupid
Felt risk of others seeing self as stupid, incapable or incompetent	15.18 20.8/29.32	undermine you…. Make you feel less than you are/ assuming I couldn't make
Being seen as lacking autonomy	20.26	therefore she can't think for herself
Perceiving family as seeing self as incompetent	20.21	mum doesn't know what she's talking
Being seen as incompetent in later life	8.7/20.13	isn't up to speed like.. younger people
Risk of being seen as incompetent increasing with age	5.48/20.26	people not believing you have a mind of your own
Low expectations of family and others	2.29/58.41	Advise me not to/ you're not cut out for
Not being seen as useful	8.35	Not seen as… just as useful
Negative response of others	2.12	he got cross
Feeling second class	11.17	Second class I suppose
Others perceiving with pity	8.34/40.21	somebody to be treated with pity
Feeling incapable owing to lack of support	2.9/ 13.16 13.29/36.6	take somebody with me /want somebody to support me to help them… feel a bit useless… not pulling my weight/ the support isn't there
Being known and recognised as capable		
Being known as valued support	23.26	don't want somebody off the street
Being real self when with known people	34.5	shell does come off…know…yeah
Letting self be vulnerable when known	30.44/31.19	I won't be afraid to say…
Felt vulnerability reduced when known	30.43	if its with somebody I know
Understanding requires being known	28.19	people… who don't know me
Expecting needs to met when known	31.1	expectation they will… accommodate
Relationship based not task focused support	23.27	don't want.. £7 an hour.. I'll walk round
Embarrassment not felt when known	31.19	wouldn't feel embarrassed or awkward
A reduced identity if not known	24.42	depends if they know you
Desire to be seen as competent and capable	25.10	competent, capable…caring... intelligent
Demonstrating capability and worth	11.28/21.47	I'm the Chair of…/ I do all the…
Recognition of capability removing need for protection	33.39	wasn't a shell… working…I knew my subject…wanted something from me
Needing to be needed	36.7	my needs in wanting to be needed
Building on existing skills and strengths	14.2/14.25	uses… skills that I've acquired… good
Supporting others	14.11	I administer…an Usher project…I work for the… support services
Negative self-perception		
History of low self-esteem	25.20	Never been… good on self-esteem
Early perception of self as unimportant	57.29	a sense you're not really important

Self as at fault	2.13/10.44	all my fault/ I'm sorry, I'm deaf
Self as less worthy than others	57.30	other people are… more important
Comparing self unfavourably to others	58.21/58.36	all my family is high achievers, but I just
Self as low achiever	1.43/58.22	not very well/the low achiever… thickie
Increasing awareness of self as different	3.31/ 7.1	well, I can't see them/ was too different
Social Interaction: difficult and risky but desired		
Missing interaction all encompassing	10.12	affects your whole outlook
Desire for any human interaction	7.27/10.11	quite like to talk to… somebody
Expressive communication as unproblematic	6.26/33.33	happy to talk… receiving back… difficult
Experiencing isolation in later life	5.48/ 21.29	isolation/ where the isolation comes in
Low self-esteem as impact of isolation	10.15	affects your self-esteem
Being in own world	11.21	Not part of the, the normal world
Communication key to being known	43.20	Actually understand who they are
Social network reduced to deafblind groups	7.30	other than with deafblind groups
Social settings as highlighting limitations	10.14	can't do, in terms of mixing with people
Increased difficulty with communication	44.9/49.27	harder to keep up…. conversations
Interaction as hard work	12.9/13.4	must get fed up… I… feel the same
Increasing difficulty engaging and making friends	6.47/ 7.10	too hard to make them/ don't know how to get to know people
Needing to have something to say	12.35	think what to say… dunno what to say
Difficulties getting to social activities	21.28	Accessing things is hard
Others inability to manage deafblindness	6.48	they couldn't cope… found it too hard
Role of communication partner	12.34	I need people to be quite chatty
Conditions needing to be right	10.5	if the conditions were right… enjoyable
Negative reaction to telling	10.27/ 10.34 10.46	they kind of stop talking to you/ I'm deaf, so he stopped speaking/ I can't talk to her
Avoiding interaction as iatrogenic risk	10.19/49.7	kind of shell round yourself
Early experience of avoiding social interaction	55.28	not mixing much particularly at school
Avoidance as ongoing experience	12.21/55.33	tend not to talk / you get used to it
Avoiding social situations	11.16/32.22	I try and avoid those/ to prevent…
Avoiding interaction albeit it desired	7.26/10.19	don't do it…leave them… I would like to
Avoiding by withdrawing	29.33/49.33	better not to engage… let them think
Avoiding interaction facilitated by volunteering	15.8	it's easy not to go out
Reducing one risk as exacerbating others	18.42/26.41	put red bands on it… No/ a dichotomy go anywhere… that's quite dangerous
Protecting self by presenting as someone else	31.39	presenting yourself… not as you really
Presenting as non-sociable: real self as sociable	10.17/31.29	be that other person… unsociable
Addressing some risks and generating others	15.8/29.35	lonely… stay indoors…nobody can get
Presentation of self as other as instinctive	33.6	more like second nature I think
Disguising impairment	9.33	just smile… just try and cover it
Avoiding telling others	11.6/28.38	I don't always, always tell people
Avoiding interaction regretted	19.31/32.46	it restricts me as well/ kind of regret
Taking an easier path as reduced quality of life	33.22	easier to watch television… certain

Taking an easier path as increased isolation	35.47	it's much easier… but it's… isolating
Social Interaction in Deafblind Groups		
Shared impairment offering sense of belonging	52.26	suppose… I do feel part of a community
Shared impairment as shared understanding	52.23	we have something in common
Avoiding risk of reduced identity	61.22	not defined by my sight & hearing loss
Ability to be self with other deafblind people	61.18	I can just be me, just be me
Being in the majority as reducing fears	60.30	wasn't scary…. other people… have loss
Communication not easier with other deafblind people	11.47 12.11	I find it hard… they struggle to lip-read/ Her speech wasn't clear… complicated
Communication with other deaf people not inevitable	12.28	even if people are deaf, it doesn't mean they're all going to… communicate
Shared impairment insufficient for friendship	7.31/ 11.46 52.24	sharing… impairment doesn't mean../ doesn't mean you are going to get on
Ongoing difficulties, changes and adaptation		
Old age and deafblindness interrelated	10.14/20.18	over the years… what… you can't do
Difficulty compensating: increasing as age	20.49/27.48	hard to read subtitles/ it does affect
Ongoing difficulties as a constant struggle	48.4/ 57.37	just gets…I've had enough/ soldier on
Difficulties as stressful	10.48/13.43	can't be doing with this/ can do without
Support as taking the pressure off	35.1	it does take the pressure off you
Constant need to be alert	17.6/39.34	you're constantly alert/ to be careful
DSI affecting all abilities	8.19	If I didn't have both… could do anything
Loss of previous coping strategies	12.46/44.9	hearing… gone down/ more than I used
Effectiveness of coping strategies dependent on actions of others	9.27/ 45.24 10.39	Tried to lip-read but she kept turning her head away/ can't cope if you don't
Sight condition as constant change	20.48/21.12	my left eye… quite a lot/ constantly
Changes in vision as gradual	21.9	happens very gradually
Awareness of increased impact of impairment	20.47/45.20	I'm aware that…watching the television
Changing hearing aids	1.36/ 4.11f	NHS hearing aids… bought me a private
Changes in technology not perceived as positive	45.1	digital came in… it was harder
Further sensory loss affecting contentment	50.46	you've lost…spoils contentment
Getting used to practically not emotionally	21.10	get a little bit more sad… each time
Getting used to as limited	11.10/21.11	used to it… it makes me a little bit sad
Ongoing need for adjustments	21.10/40.46	would adjust/adjustments over… years
Adjustment as two way	39.22	both ways… I have to… like… them to
Family members adjusting to increased sight loss	21.46 39.24	not easy being married to somebody like me/ my family's adjusted to the
Experiencing deafblindness rather than being deafblind		
Sensory impairments as separate	1.41/5.3	was just hard of hearing/ two separate
Timing of onset impacting on perception of impairment	7.7/27.43 27.45	sight issues have kicked in more now/ happened at different times…kept them
Timing of onset impacting on experience of family	40.9	sight loss.. manifesting itself until after I'd left home… no involvement with

Impairments having different trajectory	2.34/27.45	started to have problems seeing
Sight more evident than hearing loss	8.17/21.35	the deafness not so much… the sight
Mixed deterioration of hearing and vision	40.40	don't think much…hearing… vision yes
Difficulty compensating: multi-faceted	12.44/19.19 31.14 / 60.43	they can lip-read better… decipher
Ageing with deafblindness as confused identity	37.45/38.18	How have I got this age and still…
Varying hearing and sight loss impacting on identity	37.46	confused about whether I am… deafblind. I know I am, I think I'm not
Controlling self identity and defining own impairment	24.25/26.32	I would say I was hearing and sigh impaired or… sensorily challenged
Identifying as deafblind as emotive	24.7/28.2	it's quite emotive/ very emotive
Not wanting to be seen as deafblind	28.8/ 41.27	too total/ not being seen as deafblind
Desire not be defined by an unclear impairment	38.1	just sees me…isn't defined by it
Being deafblind as reduced identity	24.32	actually defining yourself as something
Legal definitions challenging perception	24.6f/28.18	I suppose I am to the DH/ legally I'm
Perception of deafblind as total as immutable	29.2	because *after all* I can see…
Having residual vision	18.13/21.2	visual acuity not bad.. I can still read
Self as more able than 'should be'	38.38	I feel guilty because I can… shouldn't
Self as unlike other deafblind people	37.36	I'm not like most other Usher… I can see and read
Later life as time of decline		
Old age as 'end of life'	56.3/60.7	it's as if I've had my life/ I *didn't* achieve
Increasing sight loss and awareness of impact	5.5/ 7.7	getting worse.. I didn't drive
Diagnosis as defining later life	3.38	be able to see until at least you're old
Reduced identity in later life	8.6/ 24.44	just see you as somebody old/ blind old
Increased isolation and loneliness	5.47/33.15	loneliness and isolation/ more isolated
Perception of self as someone in need	37.20	sense of I need help… getting old
Lost sense of direction in later life	48.14	nothing to aim for
Declining self-esteem	25.21	that's gone down as I've got older
Having regrets	25.38/58.6	regret giving up work… I regret moving
Feeling a sense of resentment	50.41/51.16	do feel a certain amount of resentment
The Significant Impact of Retirement	8.3/25.29	given up all of that/ since I retired not..
Paid employment: multiple benefits	6.16/6.22	Satisfaction / something to aim for
Work as meeting needs	6.47	it was enough… didn't see the need
Work as enabling to withstand	7.45/ 16.10	you're not dependent on anybody
Demonstrating capability pre-retirement	6.12/ 33.34	I've had a number of careers
Early aspirations	2.22	I was thinking of teaching
Retirement as loss: social support	6.24/6.34	people to talk to /camaraderie
Retirement as loss: sense of belonging	9.4	not being part of a scene
Retirement as loss: value, worth and status	5.48/ 6.24	loss of status/ are respected and valued
Volunteering later life	13.44/ 14.30	do other things for… charity/ happy to
Volunteering as fulfilling need for occupation	34.22/48.40	needed something to do
Volunteering as offering some status	13.45	actually do give me more status
Volunteering lacking recognition of paid work	26.29	recognition that paid employees get
Limitations of volunteering contributing to	15.1/ 26.32	you're not with people a

isolation	51.43-47	lot…communicating by computer.. it’s soulless/ never part of…. more isolating
Psychological Resilience		
Getting over it	55.40	but you get over it.
Keeping going: tenacity	3.43/ 5.16	I just carried on/ just getting on
Keeping going in face of feared future	56.15-22	forward to? Not a lot. But…keep going
Sense of duty and obligation	13.15	do what I have to do.
Giving up as letting others down	57.1-6	give up… you’re letting people down
Letting things go	11.10	just kind of let it go
Psychological ability to withstand risk	17.1	not going to hear… no point in worrying
Avoiding negative thinking	42.43	I don’t think about it very often

APPENDIX J

Table 14: Master Table of Super-ordinate Themes and Themes

THEME	Page/ Line
FELT VULNERABILITY AS MULTI-LAYERED: ABOUT, TO, WHEN	
Vulnerability as felt	
Mike: I've been anxious quite a lot sometimes, and the depressed feeling	11.47
Celia: I felt overwhelmed	9.36
Faye: I think it's kind of a panic feeling really	8.8
Matthew: I can get very tight and I can go, I can go from decent temperature to a bit cold	12.39
Phillip: very erm bewildered… puzzled, and confused, and hurt and upset… all these emotions	43.21-4
Anthony: so I was a little bit scared, a little bit worried	41.49-42.1
Rose: I was really very upset about the whole thing	24.33
Caroline: it was just a sense of panic.	50.11
Feeling vulnerable about	
Celia: I was thinking about the future, about my vision, it's terrifying	4.25
Faye: the other thing about vulnerability is it sort of takes on, sort of different levels… it's kind of quite a general think…feel vulnerable about your job and your future	6.25-8
Matthew: I could see with the back of my eye… I'm not sure how long that's gonna last. I'm not sure how my hearing's gonna last	79.32
Phillip: It makes me feel extremely vulnerable, yes. They all contribute to my general feeling of erm, yeah	12.24-5
Rose: It is quite a daunting thought, thought, to think that if my sight got worse and my hearing got worse, how would I manage	73.8-9

Feeling vulnerable to	
Mike: you haven’t been cooking it properly, and it's got ice in it, it can make you very ill	33.25
Celia: Just intruders coming in. I can’t hear.	15.1
Faye: I worry about falling down steps /losing… ability to, to go out, be independent… ultimately to, to look after yourself… being cut off	6.42/ 19.22
Matthew: I don’t wanna burn everything do I	60.11
Phillip: All sorts of things [pause]. All sorts of things… being attached in the street	10.32-36
Anthony: One of my vulnerabilities is isolation; it’s a big problem	4.41
Rose: that’s another thing that my, my fear of losing my hearing completely /I suppose it’s the whole thing of being taken advantage of.	30.34/ 87.24
Caroline: Of personal injury I suppose	17.11
Feeling vulnerable when: vulnerability as time, setting and situation specific	
Mike: Sometimes when it’s very windy… very windy and I’m worried…	8.46
Celia: That time… I use the free bus pass… There were four changes I had to make	9.8-10
Faye: and I just felt quite vulnerable at this particular moment	7.31-2
Matthew: Erm, when I go into hospital	10.28
Phillip: Those kinds of situations. That was one of the, one of the big ones	42.8
Anthony: I’m vulnerable, but I have a guide to take me out… Vulnerability means somebody doesn’t know what to do, whereas I know what to do in different ways... I’m not vulnerable, I think differently	31.13-23
Rose: Mostly when I’m out. I don’t think, I don’t sit and, erm, ponder over it at home but I do, it does occur to me when I’m out	30.44-5
Caroline: I don’t feel that [pause] that’s what vulnerable would mean to me… Not yet… Not yet, but it could come	15.34-44
***Social Settings*	
Celia: I’m looking around, it’s impossible. If it was one to one, say 4 to 6 feet away, I was used to that. But now, I can’t see them… I’ve given up.	25.22-6
Matthew: there was me standing on me own half the time	51.26
Anthony: they go off to someone else, and I’m left on my own	8.6
Rose: I miss out, I don’t like, err, group situations because I can’t, erm, always come, join in on the	14.20-2/ 32.8-11

conversation properly /for instance I was talking to someone, and then somebody else wants to talk to that person, they just come, come up, they im-, immediately engage with that person and you're just left standing	
Caroline: with a lot of people, and not being able to join in the conversation because it's all going too fast for me	49.27
**Losing Control and Being controlled*	
Mike: Telling me what to do… talking about my, my things that I don't want them to	9.39
Celia: But, that time… we set off, and I though 'Oh, we're going a different way /I don't want people controlling me	9.15/ 14.25
Faye: I feel vulnerable [pause] erm [pause] in situations where I don't know people, and I don't know places… Erm, everything's changing, people changing /when I was most out of my elements	6.19/ 51.31
Matthew: then someone rings up and says, 'Oh, we want you at X, Y and Z' tonight. What?! Bloody Hell! I can't do that /got that all organised and then when somethin', and then when some, you know when some doink decides they wanna do X, Y and Z… What am I gonna do... what am I gonna do, how am I gonna work this out?	61.49-62.1/ 63.1-43
Phillip: I didn't seem to know what was going on	16.36
Anthony: Vulnerability is about control, isn't it, somebody controlling	36.41
Caroline: the net effect might, might be that I would be less in control of what was happening to me and what I wanted to happen to me /and of not knowing where I was	16.12/19.9
**The Inability to withstand*	
Mike: I feel alright if I hold onto the staff	23.12
Celia: As I get older, I can't assert myself like before	3.47
Faye: as you get older, you worry about falling, you know, you don't fall over so easily/ how would I fare?	13.21-2/ 23.20-1
Matthew: I'm not err a very strong character when it comes to holding my own /some people can overcome it better than others	27.37/ 75.22
Phillip: I can't get, I can't pick the plate up on my own and move to another table. I can't see, I'm blind… I wanted to. If I could see, I would…gone the other side of the room	51.23
Anthony: I can cope with my isolation… whereas vulnerability, hmm… With isolation I help myself, I pull myself up	30.44-31.4
Rose: But then, and I suppose it's because I feel less able to cope with it now	87.28
Caroline: I wouldn't be [pause] I feel that I would be more able to hold my own with anybody else that I meet	8.21/ 23.4-9

/I don't think I'd be vulnerable to any kind of erm abuse from a communicator-guide at this point in my life… Because err I have too much [pause], because I haven't got diminished mental capacity	
*Lacking the Full Picture	
Mike: Because I can't see where it's coming from	7.24
Celia: someone approaches me from behind, I can't hear them. I don't know that they're there	4.5
Phillip: That's no good to me…. we don't where we are	10.47
Anthony: deafblind people, you don't get the full picture, you get half a picture… That's vulnerability, that's a struggle	5.10-8
Rose: Although I'd know my round the house, but if I was in a strange building. Funnily enough, but I remember some years ago… / nobody ever actually told me the importan-, the value or importance of eye contact. It just was something that gradually I became aware of… feel a bit let down because nobody did make me aware of it	16.42/ 51.19
Caroline: at risk of not knowing if the fire alarm goes off	
*Unavailable or ineffective support	
Mike: Now if you stay indoors all the time, it's not fair. You have to look on, it's like being in, in prison	32.30
Celia: I couldn't ask someone to take me to the police station to tell my daughter	9.18
Faye: just in that moment he abandoned me… so it was sort of like the crutch had been taken away	21.30-2
Matthew: No I don-, well as long as I've got my parents, I'm fine	35.43
Phillip: because the stupid buses have taken away [becomes tearful]… have taken away the temporary bus stops /It's alright for him, he can walk with his wife from the station… I can't do that	10.41/49.22
Anthony: when a deafblind person's in hospital, where's the support? If I need to go to the toilet for instance… I need somebody to guide me to the toilet. The nurses… don't feel like it's their job	42.7-10
Rose: I try as far as possible to cross at crossings… And that's one of the things where [home town] is, gives me a feeling of safety /If you've somebody designated there to do it all the time, that's one thing, but when, when you're in my sort of situation you haven't go that… that's the daunting part	30.16/ 74.1-7
Caroline: What I've found is that being connected with [charitable organisation]… you actually start to become more vulnerable, because you get this kind of acceptance… you start to accept that you need to be looked after and protected	34.29-38

Vulnerability layers as interrelated	
Celia: I hadn't seen him before, so I left it… and it was him who'd been at the door. 'My goodness, I'm so sorry'	2.49-3.3
Faye: I think maybe I missed out by doing that 14.1 /a little bit naughty in that sometimes I've taken an easier path, to avoid [pause] feeling vulnerable /until I'm allowed to be that deafblind person at work, I can't be that deafblind person /I'm glad I didn't know err sooner about my sight loss… I think it probably would have stopped me doing quite a lot	5.28-9/8.44/ 52.4
Matthew: It's probably, it's probably both to be honest	65.22
Phillip: Ah, fuck knows what he was gonna do, where I was gonna end up… Thank God on that occasion it, he actually took me to the station [pause]. Not to some stairwell or somewhere I don't know	49.11-4
Anthony: Is it wrong? Because you don't know if someone is fat or thin or [feels the interpreter's waist] or what… Did I sexually abuse you? See… Touching the body gives an image of a person	38.4-19
Rose: On the one hand, erm, it does give me a sense of security, but on the other hand, erm… I am aware of the fact that it does draw attention to me. On the other hand, that can be an advantage… but not always /but it made me [pause] very aware of my, of my weakness	36.43-37.6/ 26.28-9
Caroline: so better not to engage in conversation and let them think them think that you're snoopy, snooty /because it's much easier to do, but it's also quite isolating in itself sometimes	29.32-3/ 35.47-8
VULNERABILITY AS DEPENDENT ON THE RESPONSES OF OTHERS: MISUNDERSTANDING	
Feeling, being and expecting to be misunderstood	
Celia: They don't understand	25.35
Faye: don't want there to be any misunderstanding… people thinking I'm ignoring them /People just think I'm being… not considerate probably	32.35/ 40.41-3
Matthew: doesn't make any difference in this country… don't even know what they're doing half the time	7.45
Phillip: They think I can see a lot more than I can, and I can't /she said, 'Well, could you look at the monitor and just check what I've, what I've written please?'… I can't see the monitor, let alone what's on it!	12.44/ 30.19-20
Anthony: Yeah absolutely, because so many people misunderstand	58.25
Rose: and it made me think, well actually [pause] how many people really understood me	52.18
Caroline: for somebody to say that indicates that they don't know, they don't understand that deafblindness comes in many forms and shapes	23.45-7

Explaining misunderstanding	
Celia: Deafblind it looks the same. When you're outside, walking, you look fine. They don't know that I'm disabled, they're not aware of that	27.35-7
Faye: I didn't understand about blindness until I had to learn about my condition, so I know that there is a lot of ignorance, I was ignorant before /a difficult disability to have because it's not very, very visible	40.19/ 16.35-6
Matthew: Cos they're stupid	71.43
Phillip: Eyes are not funny or anything like that [pause]. It's a hidden thing	13.15
Anthony: you can't compare them, generally, deafblind people, everybody's different… You can't just generalise /there is no criteria to differentiate so people are often just dismissed for being disabled	33.34-44/48.31-2
Caroline: one idiotic bloke /deafblindness is a very err, it's a very emotive word and I think it doesn't convey accurately what my sight and hearing is like… I don't think it conveys to people… what it actually means… if I say I'm blind, somebody thinks, 'But you can see'	18.20/ 28.2-21
Outcomes of misunderstanding	
Celia: they don't know how to help me [multi-channel sign]	17.43
Faye: I can't use my white stick and then go into work… because people won't understand that	40.19
Matthew: I don't have problems getting on and off the buses…. but my mother always grabs hold of my arm, and says, ' Come on' and tries to make it look worse than what I think it is	24.39-42
Phillip: 'Oh. Oh really?' [pause]. 'You look alright to me', they'll say	29.36
Anthony: there's the emergency chord… I put it on top of the shelf and they told me off, and they said, 'No, it has to hang', and I said, 'No it's my mobility, I follow the wall… and I'll end up pulling it'	33.7-11
Rose: They didn't always believe what I was saying, they sort of said things like they don't believe your sight and your hearing is as bad as you think… or as bad as you're telling us /if there's somebody here, somebody here in the room with me, and something glittering on the floor, 'cos the way of the light…. shining on it, I bent down picked it up, picked it up, I would feel vulnerable, because I would immediately think, well they'll think why, why did she see that... would it be better just to ignore that and pretend I didn't see it /Well either they, they, they'd be offended or else, erm, there are, or, or else they would [pause] think I was unfriendly, unsocial /and he said, 'Go and look at the board', and I said, 'I've got a white stick… I can't see the board'	79.45/ 81.18-47 27.33-4/ 37.23-9
Caroline: putting red bands on a white cane, either people don't know what it means, or if they do know what it means, they, they won't come and help me, because they think I won't be able to hear or see anything, so there's no point / if you really were blind you wouldn't be wasting your time wearing specs would you	18.34-7/ 28.22

VULNERABILITY AS DEPENDENT ON THE RESPONSES OF OTHERS: PERCEPTIONS OF INCAPABILITY	
Feeling, being and expecting to be perceived as incapable	
Mike: [staff] talks about me, about me can't handle my money very well	8.22
Celia: It's communication, it's difficult. Think I'm stupid, but I know	13.48
Faye: blank faces looking at me as if, you know, 'Goodness me, what is she doing' sort of thing	14.26-7
Matthew: Oh God, him…. he can't do all that	69.43-5
Anthony: People shouldn't be dismissive and say 'deafblind can't, can't, can't'	48.12
Rose: I feel that people often look at me and think maybe I'm very stupid /they thought I was, nobody ever thought I was any, up to much	31.31-2/ 43.38
Caroline: I could easily be perceived as not very bright/ As I get older I can perceive that my children… might well think, 'Oh mum doesn't know what she's talking about'	8.28/ 20.19-21
Negative self-perception	
Faye: it's tricky, I, I am bumbly sometimes	40.38
Rose: I don't see myself as being, erm, highly intelligent or, or err, very good at practical things… I'm not really, I don't really shine in anything	15.38-40
Caroline: I've never been particularly good on self-esteem… I think whereas thirty years ago I would have seen myself as competent, erm [pause], err somebody's mother, somebody to take note of… I don't feel that particularly now.	25.20-5
Needing and valuing recognition of capability	
Mike: I got a certificate for [inaudible] and I got, err, a trophy. And it's a star.	30.21-30
Faye: they're quite encouraging as well… sort of say, 'well good for you being employed'	48.29
Matthew: and usually I get a very good report…. I'm the fittest person he sees	17.3
Phillip: That's what freaking keeps me, keeps me, goes back to the [inaudible] question of how do you manage to cope… and how do you feel about making you less vulnerable and coping	20.4-9
Rose: But at least I've been given the chance to give it a though, thought and try	94.1
Caroline: which in turn does meet my needs in wanting to be needed [smiles]	36.7

EXPERIENCING DEAFBLINDNESS, NOT BEING DEAFBLIND	
Sensory impairments as separate	
Mike: But the Usher caused me to go blind [pause] and partly deaf	3.17
Celia: Deaf. Strong. BSL user	18.40
Faye: it's sort of like the hearing loss comes first and then the sight loss comes later	31.4-5
Matthew: I had to have done because [pause] of [pause] my sight and hearing	38.24
Phillip: But I'm deaf and I'm blind	17.12
Anthony: because blindness is a different world again, completely different from deafness	4.12
Rose: there might be times when one is more evident than the other	50.48-9
Caroline: I think because they happened at different times in my life, I probably have kept them separate… I never thought of it as deafblindness, as a, as a whole, no, not at all	27.42-6
A mixed and unstable identity	
Mike: There's four of us blind and [pause] three can hear	2.17
Celia: I'm Deaf, I'm blind, and I've got Usher	27.41-2
Faye: I suppose now [pause] I… I see them very much together	31.22-3
Phillip: as a deafblind person, erm, I can't see /I'm blind, I'm blind	12.34/ 40.6
Anthony: Obviously because I'm deafblind I can't see	50.26
Caroline: I get confused about whether I am a deafblind person or not. I know I am, I think I'm not	37.46-7
Experiencing deafblindness as multi-faceted	
Mike: I can't see them. But I can feel them… but before you buy them you can't touch them in the shop	47.5
Celia: I'm able to see, but I'm not able to see if it's not open fully /Because it was dark… it was dark, and I couldn't make people understand what I was saying not them replying. No point writing it down	2.45/ 15.42-4
Faye: it's the worst thing that can happen to a deaf person, because they rely, they compromise, they compensate with their vision/ Erm, getting on and off buses, it's a different light condition inside the bus to outside the bus…. I don't seem to be able to look… where the pushchairs are, children	31.14-6/ 10.32-44
Matthew: We've got one near the railway station and it's not bad, but it's not in a good place at all	73.41
Phillip: It's very noisy, she talks quite softly	30.12-3
Anthony: you know when I moved here it's quite far from public transport, my friends live quite far away, so	17.12-3

that makes it more difficult	
Rose: if the rain's in my face, then the, the, it sort of spots my glasses and sort of, erm, it's just harder to see. Plus the fact that the, the road is shiny/ because one hinges on the other… Erm, so both are tied up together because now that you can't depend on the, on, you can't do that/ But because I was standing where the wind was blowing in the opposite, blowing the sound away, I couldn't hear it. And of course I wasn't near enough to actually see it in detail either	18.30-2/ 50.31/ 53.23
Caroline: if somebody has better sight than I have, or better field of vision, they can lip-read better/ I won't register what he's said, because it's dark and I can't see what he's saying/ Yes, but look just how much difficulty I had with you when you were standing with your back to the light	12.44-5/ 19.19/ 24.13-4
NEW CHALLENGES AND INCREASING DIFFICULTIES	
Ongoing and increasing difficulties as ageing	
Mike: Things became a bit hard / I can still do it. But when I could see I used to like it.	4.43/ 46.68
Celia: It was really hard work for me up until now, getting older and things / but now I need to ask	3.30-1/ 20.47
Faye: I feel now is different to how I felt five years, ten years ago, and it, it's not a nice feeling, feeling it sort of growing [moves hands over head]… not growing for the better/ it's wearing… on top form all the time	18.16-8 11.12
Matthew: I've noticed that life has got, erm, a lot harder /Oh man, it's getting erm, yeah, it's err, sometimes like a minefield / I just don't know how, how, erm, coping with it, is, is not easy	4.26/ 49.30 67.25
Phillip: it's very difficult… can be very difficult / I finally collapsed, nervous and sheer exhaustion	8.19-23/ 35.30
Anthony: my body's getting older. There's lots of risks/ I've got old… I'll have to ask people to support me	15.49-16.1/ 31.39-40
Caroline: I tend to be more isolated now than I have been for the, the very reason of the dual sensory loss	33.15-7
A complicated interaction: ageing and deafblindness	
Mike: Well since I got older, it's gone worser	3.36
Celia: I can't keep going out… I can't, four or five times a week. I can't do that	24.41-5
Faye: my parents didn't have hearing or sight problems, but you know they struggled with old age, I know that [pause] I've got that on top, a well, to come /I feel that I've got old before my time	2.42/ 20.22
Anthony: But old age, I don't know what the best… You kind of almost need a doctor to explain what getting old is, and have that done through a guide or interpreter	16.38-40

Rose: we’re talking about somebody who’s older as well, and the two merge into one	35.12-3
Caroline: people just see you as somebody old, who probably isn’t up to speed/ people say retirement’s good, you can take up old hobbies et cetera, erm, I can’t do those unless they’re, or get new ones, I can’t go out and do that	8.6/ 26.7-10
Getting ‘used to it’ as limited	
Mike: After a while, I get used to it	13.21
Celia: My eyes. They won’t get better. For a long time it’s been deteriorating… It’s awful, it’s awful	27.1-3
Matthew: Eventually you get it right	41.34
Rose: I don’t, I haven’t got used to it in the sense that it’s just as painful	78.46
Caroline: because I’m used to it. It, it makes me a little bit sad/ I probably would adjust. I’d just get a little bit more sad about it each time	11.10/ 21.10-1
EXPERIENCING CHANGE AND MAKING ADAPTATIONS	
Ageing with deafblindness: transition and change	
Mike: I used to wear one hearing aid when I was a little boy but when I grew up I started to wear two	1.24-5
Celia: My life’s changing	7.3
Faye: the peripheral vision ha-, has got worse /later in my life that the sight loss started to impinge	10.16/ 30.49
Matthew: my eyesight has changed [pause] quite a lot over the years	79.20
Phillip: So now I’m having difficulty, I can’t really read the print on the screen	38.31
Anthony: and my body’s changing yes. Age causes various pains within the body	15.47-8
Rose: That wasn’t always so, but it is now… I don’t known if my hearing will get worse, I sen, sense, I sense that it possibly will	72.43-8
Caroline: because everything happens very gradually	21.9
Ageing with deafblindness: a series of benchmarks	
Mike: Now I’m blind now	3.16
Celia: when you were here the last time, I could read with both of my eyes… But now, my right eye, I’m unable to do that… It’s got much worse.	26.29

Faye: lines in the sand, benchmarks, whatever…. you think, 'Oh, that's a new thing'… I didn't know he was there and I thought, 'Gosh, that's new'	45.32-41
Phillip: I knew my eyesight was progressing beyond a certain point	38.32
Anthony: So when I was 48, I became fully blind	4.21
Rose: there's a time when it wouldn't have been as necessary, because erm I could hear err a bit better. But now it's coming to the point where, yes, I do miss out a lot, and I worry	73.39-41
Caroline: I have to ask her to repeat it. That's not something that I think I've had to do all of my life	45.20-1
Ageing as ongoing adaptation and adjustment	
Mike: I started learning braille work	1.26
Celia: I had to keep writing things down	8.30
Faye: I mean that's the thing, you have to accommodate, err accommodate, erm compensate, erm concentrate	24.24-5
Matthew: when they decide to change things I'll need another guided tour around the building	56.14
Phillip: Getting Older? Erm, having to readjust and adapt to different changing circumstances	8.18
Anthony: It's that social interaction that I adjust, I adjust, to try and make the relationship on the same level	5.38
Rose: Yeah, I've had these particular ones [hearing aids] about 18 months or thereabouts	71.28
Caroline: because things happen gradually, I think I would adjust / So yes, I have made the adjustments over the years	39.7/ 40.45-6
TAKING ACTION TO PROTECT SELF	
Telling, educating and challenging others	
Mike: And talking about deafblind people at the University in [city]	1.39
Faye: likely to tell them… because I don't want, erm… I don't want there to be any misunderstanding /you have to educate them	32.30-1/ 40.25
Matthew: And I've told the, err, person who organised it	51.39
Phillip: So I have to keep on explaining myself to people / I've complained about this	28.35/ 10.49
Anthony: I explain to them, deafblindness is a gift, I can teach / will not allow people to intimidate… me	27.36 / 58.2
Rose: I ask people to, just bear in mind, that when they meet me out in the street or whatever, that, that they have to make the first move/ So I explained this all to them / Well, I don't think you've treated me very well	27.23/ 80.32 38.11-3

Caroline: No, get out of my space!	16.39-40
Responding to and managing risk	
Celia: With the communicator-guide I always put my… coins in the purse, and pay the bill and then put it away in my bag	20.22
Faye: I [pause] would not normally travel on my own at night, but there might be certain easy journeys that I would do /I am much more care-, careful that I used to be	15.20-2/ 43.18-46.43
Matthew: I don't do chop the carrots… and err, err grate, well grated cheese… don't wanna scrape your hand… Blood everywhere, ewwwww.	60.35
Anthony: check with me my knowledge, safety, if I know… what I think… my own safety	47.22-48.6
Rose: I don't think, oh dear maybe if I go [inaudible] somebody'll trip me up and grab, grab my handbag, or something like that… obviously I'm aware of it, of the possibility of it. But it, it doesn't stop me from doing things	29.16-25
Caroline: So, erm, I try to avoid going out at night	19.27
Maintaining connection	
Mike: so I go every Wednesday night to Deaf club	27.15-6
Celia: Yes I use WhatsApp… My mind would deteriorate [without it].	30.44
Faye: So, you know, friends are important /I think I will probably have to make an e-, an effort	27.47/ 48.3
Anthony: and they obviously have to hold my hand to show me where it is, and for a few seconds, it feels good to have that human contact... it's just good to have contact.	14.39-45
Rose: but the friends I have made over the years, and I have made lots of friends, they've been very close, erm, loyal friends	9.25
Using reserves	
Matthew: I learnt a lot about life [pause]… I learnt a few practical bits as well, which did help, that helped	85.45
Phillip: I think it's [Tai Chi] wonderful…. I have noticed erm balance, posture, circulation, and muscle tone is all improved… so if I'm on a bus and the bus jolts, and I'm standing up, without smashing my head against something… I have control of my movements	55.1-3
Anthony: to go away and to learn new things and try and build myself	19.40-1
Rose: Well, I try and look and listen as best I can	30.34

Caroline: depends on your own reading, the amount of reading you've done, your own vocabulary and how extensive it is. Because you do, you do a lot of gap filling	46.12-4
Self-care	
Mike: I listen to music…. or sometimes I get a coffee, or smoke my cigarette	10.24-8
Celia: 'Please hold on, just leave me alone'…. I want to stay in, build up my strength, hold on	4.28-30
Faye: you have to look after yourself	11.13
Matthew: I always take my, erm, MP3, plug in, plonk [mimes putting large headphones on] fine, shut out the rest of the world, cool.	17.11-2
Phillip: Err, stroking my cat…enjoying a cup of coffee… You know, it's the small things that matter really	56.30-8
Maintaining control	
Mike: I like going to [pause] erm [pause] I like doing my own things	37.28
Celia: I don't want her to pressurise me to do what she want. It's what I want. So I've had that discussion with [communicator-guide] and that's fine	24.6-9
Matthew: But I use that, not the way they taught… I just, I just hold it at an angle… And it's the way I've always done it and it works / and I've discussed a plan for eventualities	7.6-19 25.44
Phillip: Any action is then, I decide to do, decide what action should be taken.	6.6
Anthony: I'm the employer… I decide everything. I tell you, you have to do it for me, you have to follow. You don't decide for me / if you don't have a plan, you get a bit lost really… I plan everything… keep problems low	24.39 45.13-24
Rose: I will make my own decisions on who I tell / I know I could bring it into ac-, action if I need to	46.20/ 71.13-9
Caroline: I decided as well I think I'd better start using the symbol cane. I decided we need to got to a long cane…I even decided that I would register blind… it was driven by, driven by me	40.44-41.14
Demonstrating self as capable	
Mike: I give them the job as well, with [senior staff]…. I go to the business meeting	30.12
Celia: I know my own mind. I'm not stupid. I know, I do know	33.2-3
Faye: I think it could have been quite easy just to gone under with the strain	4.48
Matthew: And I jump on the stuff and I think, Oh yeah, fine, I'll do all that	69.45
Phillip: I've had articles have been published	5.36
Anthony: to learn from me… and to help them to accept my capability… People ask, 'Can you cook food? Well	49.9

how?'… I will show you.	
Rose: But I managed to keep alive… because… I didn't want to be proved right. Err, prove that, you know, that they were right, that I couldn't look after myself… It's just that that has been, if you like, a struggle with me all my life	10.28-36
Caroline: there is one… here called [name of group], which I'm the Chair of /So that's quite good, drafting and erm, letters et cetera, is one of my strengths	11.28/ 14.25
PSYCHOLOGICAL COPING STRATEGIES	
Acceptance of things that cannot be changed	
Mike: I just left it, and didn't take, didn't take any more notice	17.21-2
Faye: sometimes you think… 'why, why do I have this' sort of thing, but err, not too much of that	11.16
Matthew: I take life as it arrives and, and you could be here today and gone tomorrow like.	3.7-8
Phillip: I've resigned to it	9.8
Anthony: I accept it and don't worry about it /Positive, you have to accept getting old… It's positive to accept old age	25.31/ 32.5-8
Rose: Well I accept it	14.19
Caroline: And it did, but you get over it	55.40
Changing one's own response	
Celia: Stop doing that, change my way of thinking	6.25
Matthew: I was thinking of how I react to things and why I react to things the way I do	49.11
Phillip: and if you weigh up all your positives and you weigh up all your negatives, you should find that the positives should… be more than your negatives	56.39-48
Anthony: I can't fix the problem, what's the point in being angry [laughs] /I'm the same… but I forgave him /if I can be creative enough and get enough inspiration that it will change how I feel	9.38/ 9.46-8/ 19.45-6
Rose: And what we would now call bullying but we didn't, it wasn't recognised as bullying in those days… Erm, but I realise now that's what it was /it's actually been very good for me, because in some ways I've seen some of the bad things, erm, in a different light	3.33/ 4.9

Tenacity: keeping going	
Celia: I am determined, I can do it	32.25
Faye: I just kept going… I had to	5.1-2
Matthew: I just carry on as if life exists, well life still carries on as it were	80.21
Rose: but one way or another, I've coped with that /but I've kept up	6.48/ 10.38
Caroline: Because there isn't anything to look forward to… So, what's there to look forward to? Not a lot… But, erm, I just keep going	56.15-22
ACCESSING AND USING CARE AND SUPPORT	
Formal and informal support as positive	
Mike: I get, I like being helped… And I like being guide / use my stick and hold onto the staff	3.23-7/ 31.11
Celia: We found a communicator-guide; we go around once a week…makes a big difference, a big difference. I'm pleased, much happier / computer, iPad, iPhone… it's fantastic	5.17 30.11-34
Faye: a couple of friends at work, they look out for me, and they are fantastic	9.6
Matthew: I've got my parents… help me with various bits / I've got a white stick… it's got red, erm, stripes	3.36/ 6.27-32
Phillip: [charity] comes over to see our hearing aids… Wonderful service / I use headphones… connected to the telephone	27.33
Anthony: and it's beautiful, you can see the help, you can see the communication there… Can you see it? It's beautiful.	11.10
Rose: I have a pager, which tells me the 'phone is, and the door bell… and the fire alarm	47.33
Attributes of effective and valued support	
Celia: I know what they tell me, what to agree… we agree, decide when to go out… Control through discussion /she gave me this list, I thought 'Oh yes, interesting I've got some places to go to' and she said I have to choose myself where I want to go from the list. It's really good.	14.26-7/ 35.25-7
Faye: that's really nice, that she just instantly, erm, instinctively, err, led me away… I think. 'gosh she, she's got it… she knows what I'm up against… don't know how she picked it up so well, but she knows /they're not sort of like latching themselves on to me… they do it fairly discreetly [laughs]	17.7-20/ 42.16-7
Matthew: he spends more time with me than anybody else because he knows, cos he knows… I got a problem	20.15-8

Phillip: And then you’ve gotta level out the erm, you have to average out /she knows me and got used to me quickly, and no problem there	6.34/ 27.41
Anthony: Because she is not only a professional, she’s a professional and a human, she is both. We get on very well.	11.19
Rose: took hold of my hand and walked me through the pub… I was so relieved she did that because I wouldn’t have been able to see a thing… I couldn’t have managed without it, but I didn’t have, even have to ask her to do it, she just did, automatically did it	17.8-25
Desired future support	
Celia: I don’t want to go to an old people’s home /the old people’s home, I know I’d become very lonely	4.20/ 19.29
Faye: I think I’d be open to it [support], seeing how it goes really	50.41
Matthew: how about doing this, that and the other, taking them to places that they might not normally go to, for something a bit different /being erm, what I call, a, a, a general help when necessary /someone who will be prepared to stick up for me	76.6/ 77.26/ 27.42
Anthony: they need to understand the depth of my soul /That’s the professional business. You know, my relationship, my feelings, maybe I feel lonely, maybe I would like to go and do something that is outside of their boundaries	6.6/ 6.29
Rose: I often think it would be quite nice to have someone, or just some, something you could err, as it were, switch on, that would fill in all the gaps for me when I need them /But if I really have to use it, I’d consider asking for retraining or something	73.41-44/ 95.26-7
Caroline: want somebody that you can empathise with or who will empathise with you… You don’t just want somebody off the street, who just says given ‘em seven quid an hour and I’ll erm I’ll walk round with you, you know.	23.21-8

APPENDIX K

Table 15: Identifying Recurrent Superordinate Themes

Super-ordinate Theme	**Mike**	**Celia**	**Faye**	**Matthew**	**Phillip**	**Anthony**	**Rose**	**Caroline**	**Present in over half of sample?**
Felt Vulnerability as multi-layered: about, to, when	YES	YES	YES	YES	YES	YES	YES	YES	YES
Vulnerability dependent on the Misunderstanding	NO	YES	YES	YES	YES	YES	YES	YES	YES
Perception of incapability	YES	YES	YES	YES	YES	YES	YES	YES	YES
Experiencing deafblindness, not being deafblind	YES	YES	YES	YES	YES	YES	YES	YES	YES
New challenges and increasing difficulties	YES	YES	YES	YES	YES	YES	YES	YES	YES
Experiencing change and making adaptations	YES	YES	YES	YES	YES	YES	YES	YES	YES
Taking Action to Protect Self	YES	YES	YES	YES	YES	YES	YES	YES	YES
Psychological coping strategies	YES	YES	YES	YES	YES	YES	YES	YES	YES
Accessing and Using Care and Support	YES	YES	YES	YES	YES	YES	YES	NO	YES

APPENDIX L: EXAMPLE OF SECTIONS OF INTERIM TRANSCRIPTS OF INTERVIEWS INVOLVING BRITISH SIGN LANGUAGE INTERPRETERS

Interview With Celia

P: [Pause] So when I arrived and I sat down, [and he could sign/and we signed - check with interpreter], I was relieved, we were signing, not writing things down. Asked me if I wanted a cup of tea. So I sat down, there were other people there, I didn't know who they were, but I knew the policeman [check with interpreter - is there something here about I knew the policeman could help me?] and he was good.

I: Hmmm [pause]. What did it mean to you that the police brought you a cup of tea?

P: Cup of tea. Because they were sending a message to my daughter, and I knew it would probably take them about half an hour [and I knew they wouldn't arrive for half an hour? – check with interpreter], so that's why they gave me a cup of tea.

I: OK.

P: And also there was a real coal fire there, in the office, that's where I sat having my cup of tea [interpreter adds 'it was lovely' – is that signed?]

[D and I laugh]

Interview With Anthony

P: So I never knew I had Usher Syndrome, for many, many years. My father died when I was young, when I was nine years old, my mum died when I was about thirteen…

I: Oh gosh [not interpreted]

P: … I had to help my mother with her, her own business, with her bank account, looking after the flat, looking after her flat, you know, I had to support my mum a lot, my mum couldn't stand on her own two feet [but her family ignored/rejected her? Because? Not interpreted] she was, she was quite shy, [participant makes physical contact with interpreter – to check discussion is being followed? – then continues] quite withdrawn, so I was always trying to pull her along, and encourage her. But I'm a very open person, honestly, a very open person. I was stuck between these two worlds so…. When my mum died, I was thirteen…. In my heart I wanted to help people, and I'd learnt that from my mum and dad, you know, regardless of the break down in communication. You know, all Deaf people have the same problems; Deaf sometimes get angry and [interpreter checks meaning of next 'sign', participant fingerspells bitter] bitter [participant states he does not know the sign for 'bitter', uses his own sign – interpreter demonstrates BSL sign for bitter]. So people would talk, you know and say bad things, and I would try and say to them, 'No, no, no', you know, and try and teach them, and try and help them to understand, because they didn't know how to cope with deafness, they didn't know how to cope with life, with communication. You know, my father did give me a lot of wisdom. You know he'd say please forgive me I don't have the, you know the education, and I'd try and help people with that, so he'd got a good feeling [Participant makes physical contact with interpreter – to check discussion is being followed? –interpreter signs 'good, thumbs up' – participant then continues] He was very considerate, very considerate my father. And he had his own weakness [Participant fingerspells 'weakness' then signs 'weak']…

When I was twenty-two years old, I went to America, and gave a presentation to the public, [interpreter stops and checks for meaning of next signs] and I fell down some steps, and I didn't know what was wrong with me, but I realised that my vision… that there was kind of blackness [Participant and interpreter indicate with their hands a 'tunnel shape' in front of the face] in the peripherals of my vision, and I saw an eye specialist and they told me that I had Usher syndrome, but you know, I didn't know what that was, that it was progressively going to make me blind [Participant signs, it was a shock to me? not voiced over]. You know it reminded me of my mother and father, and it's really difficult them trying to explain to me my eye problems, I remember the difficulty for them trying to explain my eye problems. And they didn't share that with me and I don't know, I do understand that I suppose. But for me, when I found out I had Ushers, when I was going to go blind, it made me feel quite low, it was because my parents [Participant actually signs 'father'] didn't tell me straight away. And people think, you feel helpless; you know people don't know what to say. You know, people who had known me since I was a child. It's easier just to not think about these things, you know, you think you can just do everything, and try and do everything, and you have to be realistic, and you know, and accept that there's an issue or a problem. When I lost my sight, I was quite fortunate, it was quite a short [interpreters states tumor, questioningly – interviewer intervenes – is it trauma? – interpreter checks with participant – participant fingerspells TRAUMA] so it was quite a short trauma, losing my sight, you know, it didn't take a long time, it was quite positive I suppose [participant signs in mind? positive thinking?] and I had to accept I was going blind and I was reflecting on my father telling me, or telling someone that I was blind, and you know, you have to accept it, and think positive.