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Parental participation in Speech & Language Therapy (SLT) treatments in young children with Speech, Language and Communication Needs (SLCN) levels, predictors and relations with child outcome

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**Parental participation in Speech & Language
Therapy (SLT) treatments in young children with
Speech, Language and Communication Needs
(SLCN): levels, predictors and relations with child
outcome.**

Penny Williams

**Thesis submitted for the degree of Doctor of Philosophy of the
University of London**

27th January 2017

**Institute of Psychiatry, Psychology & Neuroscience
King's College London**

DEDICATION

“To teach is to touch lives forever”

S.M. Scott

For my Dad

Bernard Williams

(8th March 1938 – 20th June 2015)

“He who has a why to live for, can bear almost any how.”

Friedrich Nietzsche

For my girl, my ‘why’

Lara

ABSTRACT

Between 5-8% of young children have Speech, Language, Communication Needs (SLCN); persisting SLCN has long-term effects on social, emotional and educational development. Speech and Language Therapy (SLT) is central to the diagnosis and of therapy for such children. Efficacious interventions require that a participant is both present and engaged and in young children parental involvement is necessary, however, little is known about parent participation in SLT. This PhD comprised a 3-phase study designed to identify levels of parental participation in SLT interventions with children (<5 years); identify predictors, and explore child outcome-participation relationships following therapy.

Phase 1 was a qualitative interview study with parents classified as consistent or inconsistent attenders, to explore parental engagement. Three super-ordinate themes were identified capturing all views relating to parents beliefs, emotions and experiences. Differences between groups indicated that early recognition, active referral-seeking and a parental belief in their role in the cause and solution may motivate attendance. Some degree of self-doubt about parenting skills may have been a motivating factor.

Phase 2 involved the development and piloting of the IPQR-SLCN, a self-efficacy measure, satisfaction scales and an assessment of the appropriateness of the main outcome measures to be used in Phase 3.

Phase 3: This cohort study explored the predictors of attendance, adherence and relationships with child outcome. Parents completed a range of questionnaires at two time points (baseline N=199, follow-up N=148) to assess the influence of factors within the domains of *parents beliefs* (illness perceptions, self-efficacy), *personal circumstances* (socio-demographics, family functioning) *treatment experience* and *child factors*, on participation and child outcome. Predictors of attendance, adherence and outcome were identified through multiple regression analyses. The main predictors of attendance included maternal age, education level and two factors within the parent beliefs domain. Parental rating of the importance of a recommendation and specific self-efficacy beliefs predicted adherence. Child factors, parent beliefs and satisfaction with treatment predicted child outcome. Neither attendance nor adherence predicted child outcome.

This thesis presented the first evidence for what motivates parents to participate in their child's SLT. Further research is required for the generation of a comprehensive model of

participation in SLT and to development interventions for enhancing participation. This thesis raised questions for the SLT profession about the assessment of young children, the identification of those who require specialist interventions and the issue of dosage.

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ABBREVIATIONS

Abbreviation	Meaning
ADHD	Attention Deficit Hyperactivity Disorder
AHP	Allied Health Professionals
AIC	Akaike's Information Criterion
ASD	Autism Spectrum Disorder
BIC	Bayesian Information Criterion
BTP	Barriers to Treatment Participation
CBT	Cognitive Behavioural Therapy
COM-B	Capability, Opportunity Motivation – Behaviour
CSPQ	Consumer Satisfaction Parent Questionnaire
CSQ8	Client Satisfaction Questionnaire
Dadh	Degree of Adherence
DNA	Did Not Attend
DSM	Diagnostic Statistical Manual
EPRS	Electronic Patient Record System
EUQ	Empathy and Understanding Quotient
FLQ	Family life Questionnaire
FOCUS	Focus on the Outcomes of Communication Under Six
GAS	Goal Attainment Scaling
GLM	General Linearised Model
HRS	Homework Rating Scale
IPQ-R	Illness Perceptions Questionnaire – Revised
IPQR-SLCN	Illness Perceptions Questionnaire Revised - Speech Language Communication Needs
KMO	Kaiser-Meyer-Olkin
M-ATIF	Modified-Adherence Telephone Interview Form
MCID	Minimally Clinical Important Difference
MH	Mental Health
NHS	National Health Service
PCI	Parent-Child Interaction
PETS	Parents Expectancy for Treatment Scale
PSOC	Parenting Sense of Competence Scale
RCT	Randomised Control Trial

SCT	Social Cognitive Theory
SEPTI	Self-Efficacy for Parenting Tasks Index
SES	Socio-Economic Status
SE-SLTR	Self-Efficacy –Speech Language Therapy Recommendations
SLCN	Speech Language Communication Needs
SLI	Specific Language impairment
SLT	Speech and Language Therapy
SLTherapist(s)	Speech and Language Therapist(s)
SRM	Self-Regulation Model
TA	Therapeutic Alliance
TASCP	Therapeutic Alliance Scale for Caregivers and Parents
TOPSE	Tool to measure Parenting Self-Efficacy
VIF	Variance inflation factor
WAI-S	Working Alliance Inventory-Short Form
WHO	World Health Organisation

INTRODUCTION TO THE THESIS

The empirical research in this thesis focuses on parental attendance and adherence to speech and language therapy (SLT) interventions in young children. Parents make the decision to bring their child to treatment, and with the expectation of parental involvement in this age group, implement therapy at home. The significant negative effects of missed health appointments or non-adherence to treatment have resulted in a wealth of research in other areas such as medication adherence. Increasing attention has also been given to other types of treatments including psychological interventions and physiotherapy, particularly in adult patients. A smaller evidence base of participation research exists in children, adolescents, and parents. There has been little exploration of these phenomena in SLT.

Structure of the thesis

The literature review (chapters 1-3) provides background information on child SLCN and SLT interventions in young children, highlighting the necessity for understanding parental motivation to engage in SLT. In the absence of participation studies in SLT, the literature review synthesises research from a broad area, beginning with attendance, followed by adherence. It necessarily includes evidence from adult literature, but where possible focuses on research conducted into parent participation in child psychological treatment. A discussion of theoretical models that are associated with treatment participation follows (Chapter 3). Due to the limited participation research in SLT, the approach to the literature review was scattergun; the searches are defined at the beginning of each Chapter (1-3) but were iterative and overlapping. The review concludes with a summary of the literature and the implications for the present research (chapter 4).

Chapter 5, the first empirical study (Phase 1), is a qualitative study, beginning with a review of the literature of parental experience of SLT. It examines the different experiences of parents' dependant on their level of attendance. With the identification of relevant factors associated with non-participation in the literature review and qualitative study, Chapter 6 reports on the measures selected for use in the main study. Chapter 7 is the second empirical study (Phase 2), piloting the scales used to measure adherence, satisfaction, and a self-efficacy measure developed specifically for this research. Chapters 8 -10 represent the final empirical study (Phase 3) of this thesis. Chapter 8 reports on the design and methodology, Chapter 9 the

results, which are discussed in Chapter 10. Finally, Chapter 11 discusses the whole thesis, including limitations and recommendations for future research.

CHAPTER 1

1. Speech, Language and Communication Needs (SLCN)

Overview of Chapter

This Chapter provides an introduction to SLCN including aetiology, prevalence and the subtypes of SLCN. The second section is a brief discussion of SLT interventions with young children, the role of SLT and parents, and lays the foundations for the value of understanding parent participation in this clinical area.

Relevant literature was obtained from a non-systematic search of four databases (Embase, Medline, PsychInfo, CINHAL) using search terms referring to the different types of SLCN (language, speech, dysfluency) combined with 'delay' OR 'disorder' OR 'impairment' AND 'child'. Searches were further refined with the addition of terms such as prevalence/natural history, aetiology/ risk factors, intervention/impact/outcome and finally cost effectiveness/efficiency. Searches were limited to papers published post year 2000. To ensure the highest quality evidence was available a separate search was conducted for systematic reviews of any SLCN, with no restriction on publication year. Abstracts were screened for relevance and papers excluded if they did not relate to SLT or children or to the specific search terms. Where possible only the highest quality and most up to date evidence available were included.

1.1 Introduction to SLCN

SLCN can be primary or secondary to other cognitive, sensory and physical conditions (Bishop & Norbury, 2009; Slonims & Pasco, 2009). Socio-economic status is also implicated with high levels of SLCN identified in areas of high social disadvantage (Law, McBean, & Rush, 2011). These conditions within SLCN are not mutually exclusive, with significant co-morbidity and continued debate about the specificity of definitions of some disorders (Bishop, Snowling, Thompson, & Greenhalgh, 2016; Bloodstein, 2006). More boys than girls are thought to have SLCN with ratios of 2.5-4:1 reported; with the variation based on which aspect of communication was being measured, methodological differences, and potential underreporting in girls (Dale, Price, Bishop, & Plomin, 2003; Law, Boyle, Harris, Harkness, & Nye, 2000).

Between 5-8% of young children will have SLCN (Law et al., 2000). Prevalence rates over a 30-year period have remained static (Law, et al., 1998; Law et al., 2000), although changes in definitions of some disorders may influence estimated prevalence. Using the most recent Diagnostic Statistical Manual (DSM 5) criteria, a recent study investigating the prevalence of language disorders in a large sample (N=7267 screened, n=529 assessed) of children (4-5 years), estimated prevalence of this specific type of SLCN as 9.92% (Norbury et al., 2016). SLCN can have a significant impact on social, emotional and educational development (Botting, Durkin, Toseeb, Pickles, & Conti-Ramsden, 2016; McCormack, McLeod, McAllister, & Harrison, 2009; Snow & Powell, 2004; Young et al., 2002). In adulthood communication impairments affect the social and economic status of an individual, increasing the risk of unemployment (Ruben, 2000) and a significant proportion of individuals aged under 18 in young offender institutions have a SLCN (Bryan, Freer, & Furlong, 2007). The demand on services to meet the needs of this population is significant across all ages.

SLCN can be differentiated according to the primary area of difficulty: language, speech and dysfluency (stammering). In each of these areas the aetiology is not yet fully understood, but there is a consensus that genetic and environmental influences are important (Felsenfeld et al., 2000; Kovas et al., 2005; Lai, Fisher, Hurst, Vargha-Khadem, & Monaco, 2001; Newbury et al., 2002). Genes play a role in the susceptibility to SLCN. It is not thought to be a single gene disorder despite the identification of one family where a single gene has been implicated (Bishop & Norbury 2009). Recent research has also provided supportive evidence of the role of common copy number variants (repeated sections of DNA) in contributing to the risk of one

type of SLCN: Specific Language Impairment (SLI) (Simpson et al., 2015). As with genetics, environmental factors alone cannot explain some of the selective deficits in areas of language in SLI such as grammar and phonology, but could be implicated in early language delay (Bishop & Norbury 2009). Environmental factors such as parental input may have greater influence on some components of language development than others (Kovas et al., 2005). Research into the relationship between socio-economic status (SES) and language impairment has delivered mixed results. For example Hoff and Tian (2005) suggest that language is mediated by the level of maternal education with others suggesting that a high SES (as well as pro-social adaptive communication) were protective factors (Paul, Bishop, & Leonard, 2000) or not a predictor of long-term impairment (Dale, Price, Bishop, & Plomin, 2003). The cause of SLCN is multi-factorial involving the combined effect of many genes and the environment.

A significant proportion of young children presenting with SLCN of unknown aetiology will have difficulties that resolve spontaneously. Cited figures for spontaneous resolution include, 44% with language difficulties (Law et al., 1998, Law et al 2000); 50% with speech disorders (Stein et al., 2011); and 65-80% with stammering (Howell, Bailey, & Kothari, 2010; Yairi, 2005). However, although some methods are available for distinguishing between those whose difficulties will resolve and those in whom they will persist (e.g. Bishop et al., 2012; Everitt, Hannaford, & Conti-Ramsden, 2013), they do not appear to be in routine use. Clinical services are therefore at risk of treating many young children with SLCN that will resolve spontaneously. This has resource implications and furthermore there are ethical issues such as providing intervention when none is required and raising unnecessary anxiety within the family.

1.2 Interventions for SLCN in young children

Efficacious interventions are essential in providing the best outcomes for children, and speech and language therapists (SLTherapists) are the main professionals involved in diagnosis and therapy for children with SLCN. A Cochrane review indicated that SLT can be effective for speech and expressive vocabulary difficulties, but showed less clear results for expressive syntax difficulties and a lack of evidence for receptive language difficulties (Law, Garrett, & Nye, 2003).

Involving parents is highly valued by the profession, is considered integral to clinical practice (Carroll, 2010) and an important component of delivering evidence based practice (Roulstone, 2011). Parent-mediated SLT interventions are increasing and continue to be developed in response to the established belief that learning should occur within a child's natural environment and that communication development is founded in reciprocal interactions with caregivers (Mahoney et al., 1999; McLean & McLean, 1999). Parental involvement is an important factor in supporting the intensity and generalisation of intervention with evidence demonstrating that the involvement of parents can result in improved outcomes over treatment by a SLTherapist alone (Hampton & Kaiser, 2016).

How parents are involved varies, for example where an intervention is primarily delivered by a SLTherapist, additional practice at home is expected and homework commonly provided (Pappas, McLeod, McAllister, & McKinnon, 2008; Sugden et al., 2016). Alternatively parents may receive training in how to deliver an intervention at home. These interventions are often focused on enhancing the quality of parent-child communicative interactions, regardless of the nature of the SLCN and range from brief parent training groups to individually tailored parent-child interaction (PCI) treatments. The intention is not to indicate that parent communication style is responsible for SLCN rather it is in recognition of the bidirectional influence in interaction between children and parents. The nature of SLCN in a child will necessarily affect their communication and interaction with their parents which, in turn, influences the communication style of parents. These PCI interventions typically aim to increase the quality and frequency of interactions, the responsiveness of the parent, the intensity and quality of the language input and enhance the use of natural language support strategies (Roberts & Kaiser, 2011). Research has demonstrated the efficacy of PCI treatments (e.g. Baxendale & Hesketh, 2003; Jones et al., 2005; Pickles et al., 2016; Roberts & Kaiser, 2011), although, as with many interventions in SLT, manualised PCI treatments are often modified to match available resources (Law & Conti-Ramsden, 2000; Ruggero, McCabe, Ballard, & Munro, 2012).

SLTherapists are skilled at assessing child factors and providing interventions, and recognise the need to engage parents at all points in the therapeutic process including both planning and provision. However, there can be a difference between SLTherapists' intention and actual practice with parental involvement in planning most affected (Pappas et al 2008). In Pappas and colleague's (2008) qualitative study, SLTherapists expressed dissatisfaction with the level of parental involvement and referred to personal, service (inflexible service delivery options in schools) and parent factors (time, beliefs and capability) as barriers to achieving acceptable

levels of involvement. Personal barriers for the SLTherapists also included having insufficient time as well as beliefs and lack of experience in involving parents (Pappas et al 2008). Intervention is therefore often based on child need and resources available, rather than accounting for parental preference or ability to participate in the treatment. SLTherapists also balance competing demands on resources including staff, waiting lists and caseload sizes (Sugden, Baker, Munro, & Williams, 2016) and when an ideal intervention is not immediately available, alternatives may be offered so that the child receives a range of treatments for the same condition. Parent mediated interventions are ubiquitous despite research suggesting they may not be suitable for all families (Baxendale & Hesketh, 2003; Birkin, Anderson, Seymour, & Moore, 2008) or for some children (Carter et al., 2011).

Parental satisfaction and experience of SLT has been explored, with the majority of studies using qualitative designs (see section 5.1). Differences between parents and practitioners in the beliefs and practice have been revealed and suggest that these may negatively affect interventions and influence collaborative working (Lindsay & Dockrell, 2004; Marshall, Goldbart, & Phillips, 2007). Consistent across these studies is the recognition and recommendation that SLTherapists need to discuss parental expectations and beliefs and consider their individual circumstances to ensure optimal uptake of therapy (e.g. Carroll, 2010; Glogowska & Campbell, 2000; Sugden et al., 2016). Despite the availability of such rich information, the relationship between parental beliefs and experiences, their involvement in intervention and child outcome, has not been systematically explored and non-attendance continues to be a challenge for service delivery.

Conclusion

SLCN represents a broad category of needs; causation is multifactorial including genetic and environmental factors and persistent SLCN can have long term effects. In young children a significant proportion will spontaneously resolve, however, the means of identifying this group do not appear to be in routine use. SLT is the main provider of treatment for this group and interventions for young children can be parent-mediated or involve parents in carrying out practise at home. Despite the importance given to engaging parents by the profession in all levels of decision making in their child's care, SLT research indicates that this is not routine practice. Intervention is often offered based on child need and availability of resources without recourse to parent choice or preference. SLT research has highlighted differences between parent and professional intervention beliefs and raised the possibility of their negative influences on collaboration and uptake of therapy. A systematic exploration of parent participation in SLT has not been undertaken.

CHAPTER 2

2. Attendance and Adherence

Overview of Chapter

This Chapter introduces the concepts of attendance and adherence and their inter-relatedness. For each, how these concepts are defined and measured is discussed and identified rates included. The impact of failure to attend and adhere on services and patients is discussed and the literature related to the predictors of non-attendance and non-adherence is reviewed.

Relevant literature was obtained from four databases (Embase, Medline, PsychInfo, CINAHL) using search terms referring to: 1. attendance/drop-out/missed appointments, 2. adherence/compliance/persistence/concordance/homework completion; 3. engagement/participation. Searches were further refined according to the nature of treatment: speech/language/dysfluency intervention, medication, psychological, behavioural and physical such as exercise, and/or recipient of treatment: child OR adult, and/or facilitator of treatment: parent/carer. There were no restrictions applied as to the year of publication to allow the broadest search, particularly for SLT related research. Abstracts were screened for relevance and papers excluded if they did not relate the search terms used. Papers were included based on their level of quality and/or relevance to SLT, with priority given to systematic reviews, meta-analyses, RCT's and reviews. Lower quality studies were retained in certain areas where literature was sparse and/or had particular relevance to SLT.

2.1 Introduction

An efficacious intervention requires that a participant is both present and engaged. In the case of young children it is the parents who bring them to treatment and who play a significant role in engaging in the intervention. Seeking help in the first instance is also important and may be driven by parents, or by others including other health professionals (health visitors, GP, community paediatricians) and other family members, but it is not a primary focus of this current research. Similarly, although children themselves contribute to the engagement process, their role is also not considered in this thesis.

Attendance and adherence are related, but distinct concepts. A recent review of adherence papers in child psychiatry found that 25% of the articles included examined links between these two constructs and all found that an increase in attendance was related to an increase in adherence (Haine-Schlagel & Walsh, 2015). Non-adherent parents (N=27) have also been found to prematurely terminate behaviour management treatment for their child (2.3 -13.8 years) (Chamberlain, Patterson, Reid, Kavanagh, & Forgatch, 1984). Chamberlain et al (1984) described intervention resistance and co-operation rather than using adherence terminology, although their concept appears synonymous. They reported that co-operative parents (54%) were more likely to complete treatment than those described as resistant (14%). Some authors suggest that actually engaging in treatment is of greater benefit in predicting treatment outcome (Clarke et al., 2015; Nix, Bierman, & McMahon, 2009; Nock & Ferriter, 2005). In interventions involving parent education and training, adherence has been shown to significantly predict outcome over attendance (Clarke et al., 2015; Nix et al., 2009). Both attendance and adherence are clearly important in understanding how participation in an intervention affects outcome.

What follows is a limited review of the literature related to first attendance, followed by adherence, including definitions, impact, relationship to outcome and predictors. 'Participation', a term of convenience, will be used to denote the combined effects of attendance and adherence. As relevant literature in SLT is limited, the review incorporates adult and paediatric, medical and psychological research. Of these, studies that are the closest to SLT in their interventions are paediatric psychotherapeutic interventions, particularly in the treatment of autism. Parallels can also be found in physiotherapy with respect to homework completion and the behaviour change required.

2.2 Attendance

Definition: Attendance can be defined as the recipient of therapy going, or the case of children 'being brought' to a location for a pre-arranged appointment with a professional; conversely non-attendance is the failure to turn up (Nock & Ferriter, 2005). Descriptions of non-attendance vary relative to the stage of service delivery, such as failing to attend an initial assessment and/or subsequent intervention sessions. Examples in the literature include looking at the total number of sessions missed (Carr et al., 2015); looking at drop-out rates where drop out is defined as attending at least once (e.g. Luk et al., 2001) or alternatively pre-treatment dropouts where no sessions are attended at all (Curran, Flynn, Antonijevic-Elliott, & Lyons, 2015; Fernandez & Eyberg, 2009). Rates of attendance also differ between efficacy and effectiveness studies with lower rates observed in the former (de Haan, Boon, de Jong, Hoeve, & Vermeiren, 2013). In clinic there are also groups of patients who can best be described as inconsistent attenders whereby they attend a few sessions, miss some, but usually return. This phenomena has been described in adult psychiatric patients with one study reporting seventy one per cent of missed appointment were re-booked (Sparr, Moffitt, & Ward, 1993).

Rates: In the UK, non-attendance research related to children is limited, with a recent review highlighting the need for further investigation (Arai, Stapley, & Roberts, 2014). In paediatric SLT, only three studies were located that specifically examined attendance with only one from the UK. Many SLT services are required to report attendance figures locally, but this information is rarely of public record. The SLT service from which participants in this thesis were recruited provided a non-attendance figure of twenty percent (N=21,905 appointments) for the whole service in one year (2013 -2014). Of the published studies in paediatric SLT one small study (N=32), based in the US, explored the social validity of a parent mediated language intervention and reported completion rates rather than attendance. Completion was defined as attending more than nine out of twelve sessions; 28.9% did not complete the intervention (Girolametto, Tannock, & Siegel, 1993). In the UK a study examining the caseload characteristics of a SLT service reported non-attendance rates of 14.9% for a sample of 1100 referrals (Broomfield & Dodd, 2004). Both the population and the service under study were comparable to that in the present thesis, representing a deprived, ethnically diverse, inner city population, although also including rural areas. The most recent study, conducted in Ireland, was aimed at examining pre-treatment drop out rather than total non-attendance and cited a figure of 17.9% (N=140) who failed to attend their first appointment (Curran et al., 2015).

Given the limited studies available in SLT a broader paediatric literature was considered. Rates of non-attendance in the paediatric population have been reported across different service areas for example 20.4% in US paediatric primary care (Samuels et al., 2015) and 19.8% in a rural paediatric community healthcare centre (Sherman, Barnum, Buhman-Wiggs, & Nyberg, 2009). Research into child and adolescent psychiatry and psychology services report rates of 13% (US) (Gordon et al., 2010) and in the UK a rate of 14.7% for missing an initial appointment and 15.6% at follow up (Mitchell & Selmes, 2007). In adults, higher rates of non-attendance in out-patients have been reported in psychiatric populations as compared with other medical specialities, 19.1% compared to 11.7% (Mitchell & Selmes, 2007), but a simple comparison of the primary care versus psychiatry rates reported here suggests the opposite may be true with children. Not accounting for the variability in attendance measurement, service delivery, and child condition, reported non-attendance rates appear to be between 13-20% for paediatric populations.

Impact-service: The consequences of missed appointments are significant and affect healthcare organisations, professionals and patients themselves. Lost productivity due to appointments missed, but not refilled has financial implications for organisations such as the National Health Service (NHS). This negatively affects waiting list length and, as longer waits is associated with an increase in missed appointments (Sherman et al 2009), risk a self-perpetuating cycle of non-attendance. In the period 2013-2014 the cost of missed appointments across the NHS was estimated to be £225 million (Morse, 2014).

In the NHS, service delivery protocols are frequently put in place to minimise cost pressures associated with missed appointments. One such procedure is the requirement of patients to give at least 24-hours' notice prior to cancellation to allow re-utilisation of the slot. Where this notice period is not met, services will classify this missed appointment as a 'Did Not Attend' (DNA). A DNA will trigger a procedure whereby a patient will be notified that missing two further appointments (and in many cases just one) without making contact will result in discharge. Patients can be re-referred, but then move to the end of any waiting list. This approach can disadvantage patients, does not account for the reasons why people miss appointments and following this procedure can result in high risk patients (either medically or socially) not being identified (Powell & Appleton, 2012). Genuine reasons for lack of contact may not be recognised leading to frustration and potentially reducing satisfaction with services (Powell & Appleton, 2012). The term DNA is not unknown to patients and some have viewed it as punitive where valid reasons to not attending exist (Arai et al., 2014). Other approaches

include 'opt in' methods where, on receipt of a letter, patients are to contact the service within a specific time-frame to request an appointment. Failure to do so also results in discharge (e.g. Curran et al., 2015). Other services, such as the one in this study, combine both systems. Relying on written communication requires competence in reading English and risks excluding families with literacy difficulties or where English is an additional language. The combined effects of these approaches may actually result in longer waits, dissatisfied patients and poorer health outcomes.

Impact- Healthcare Professionals: Non-attendance also affects health professionals' perceptions of patients. In a review of non-attendance in the adult psychiatry population, an increase in negative attitudes, frustration and lowered empathy towards their patients was reported (Mitchell & Selmes, 2007). Health professionals are not without empathy but also make general assumptions about the underlying reasons for missed appointments, which can contribute towards a negative perception of patients following DNA. A recent qualitative study in one city in the UK, considered health professionals' views (GPs, hospital clinicians and management staff) of non-attendance in general paediatric outpatient clinics (Cameron et al., 2014). Different perspectives were highlighted between the groups, however, a common view was that non-attendance features in families with chaotic lifestyles and those experiencing socio-economic disadvantage and, for certain groups of HCP's, non-attendance raised concerns about safeguarding. Although the expressed views are not necessarily inaccurate, participants' responses were more nuanced, with somewhat negative language used such as "repeat offenders" (Cameron et al., 2014 p.116). Patient awareness of the term DNA, and that professionals can hold negative beliefs about non-attendance, risks future relationships with services.

Impact treatment: Missed appointments may affect treatment intensity and the delivery of optimal intervention. Patients may not benefit fully from treatment guidance leading to more self-directed treatment recommendations affecting the efficacy of the intervention (Mitchell & Selmes, 2007). Defining optimum treatment through research can also be affected by non-attendance as research participants who are lost to follow up or drop out can result in biased samples, reduce the power of studies and thus limit the generalisability of results (Nock & Ferriter, 2005). A further limitation is the omission of measurement during intervention research, for example in autism, where it can affect the quality of the evidence with implications for clinical practice (McConachie, & Fletcher-Watson, 2015).

In SLT the correct dosage is not always certain (Law et al., 2004) and is dependent on various factors including clinician factors, treatment, child severity and presenting conditions. A meta-analytic review of the efficacy of interventions for developmental speech language delays/disorders tentatively suggested that the most effective SLT interventions were over eight weeks in duration, although those which were of longer duration were not always the most intensive (Law et al., 2004). A scientific forum in SLT concluded that the relationship between intensity of interventions and clinical outcome was most likely non-linear (Baker, 2012).

Within the psychology literature the relationship between dose and intervention is also equivocal with some studies reporting no relationship, others a positive one and some suggesting that lower intensity treatments are more beneficial and that consistency in attending may be more important than the actual number of sessions or time spent in treatment (Nock & Ferriter, 2005). In the paediatric literature smaller doses have also been shown to be beneficial for children who are less severe and with parents without any psychopathology (Nock & Ferriter, 2005) and in parent interaction interventions a meta-analytic review indicated that the most successful interventions were not necessarily those with the highest number of sessions (Bakermans-Kranenburg, Van Ijzendoorn, & Juffer, 2003). Finally, in a large study (N=592) of children (5-17 years) receiving mental health (MH) treatment, no dose-outcome effect was found when children receiving few outpatients appointments were compared with those receiving more (Andrade, Lambert, & Bickman, 2000). Knowing what level of intensity is required to achieve optimal outcome is uncertain and it is important to acknowledge that more is not always better. It is possible that in SLT missing appointments later in treatment may reflect a parent's active choice to end an intervention because they perceive it is sufficient for their child's needs. Understanding how attendance relates to outcome and if it is mediated by parental treatment beliefs would be beneficial to patients and services.

2.2.1 Predictors of attendance:

Studies have examined correlates and predictors of attendance which can be classified into patient/family-related factors, child-related; and service-related. Variables associated with non-attendance have also varied depending on stage of dropout such as early versus late (Kazdin & Mazurick, 1994).

2.2.1.1 Patient /family Related

Socio-demographic: Higher levels of deprivation have been shown to be associated with lower levels of attendance both in adults (Mitchell & Selmes, 2007) and children (Nock & Ferriter, 2005) and in PCI treatments for young children (3-6 years) with behaviour problems (Fernandez & Eyberg, 2009) across a variety of psychiatric populations. Other studies however, have shown no relationship or that higher SES is associated with non-attendance, which may suggest a curvilinear relationship (Kazdin, 1996). Indices of deprivation vary potentially influencing interpretation, with predictors of non-attendance including urban residence, minority status, single-parent status, and medicaid status (e.g. Armbruster & Schwab-Stone, 1994; Kendall & Sugarman, 1997). One study in particular is of interest due to the overlap in populations and treatments with the current research. Carr et al (2015) examined associations between attendance, adherence and outcome in a Randomised Control Trial (RCT) of young children (2-5 years) receiving interventions for Autism Spectrum Disorders (ASD). Participants were randomised to receive one of two treatment groups differentiated primarily by mode of delivery: individual parent mediated and group parent education. In this study the significant predictors of attendance were SES, where lower levels of deprivation predicted better attendance, as well as treatment condition and site (Carr et al., 2015).

As noted previously, missed appointments can sometimes raise concerns in health professionals about safeguarding a child and indeed statutory definitions of neglect recognise this as a child protection issue (Powell & Appleton, 2012). Evidence for this position comes from the findings of serious case reviews in the NHS where overall disengagement with services features in these families (NSF CYP maternity 2004). In the attendance literature this finding has not been prominent; however, Watson and Forshaw (2002) reported that one third of children who missed appointments were known to social care. It may be that the finding that deprivation can predict non-attendance accounts for this lack of focus. The relationship between economic disadvantage and the well-being of the child is known, for example in a large UK study, a strong relationship was found between the number of deprivation indices and the risk of maltreatment (Sidebotham, Heron, & Golding, 2002).

The relationship between ethnicity and non-attendance has also been considered but with some studies reporting higher non-attendance in minority groups and others finding no association. Sherman et al (2009), in their paper examining the influence waiting times have on treatment uptake in a rural child and adolescent MH centre, found that the odds of

minority status youths attending an appointment was two-thirds (67%) that of non-minority youths. Referral source (where youths were mandated to attend) was also a significant contributor to non-attendance along with waiting time. A limitation of this study however, was the unequal size of the different ethnic groups, with the largest being Caucasian (72.0%) followed by African-American (17.8%), and Hispanic (3.5%). Another USA study explored the effects of ethnicity on attendance, treatment and outcome with children (age 7-9.9 years) and parents (N=579) participating in an RCT of multi-modal Attention Deficit Hyperactivity Disorder (ADHD) treatment in adolescents (Arnold et al., 2003). The frequency of missed appointments to parent training sessions was slightly higher in the African-American group, but this was a non-significant trend. Included ethnic groups were Caucasian, African-American and Latino. Both these studies acknowledged the potential of SES acting as a confounder in their analyses yet the findings remained the same when this was controlled for.

Patient age has also been highlighted as relevant to attendance and results differ between children's and adults' appointments and by medical condition. In a study aimed at understanding non-attendance in a large paediatric medical centre in the USA, increasing age of the child, along with type of appointment significantly predicted non-attendance (Samuels et al., 2015). In adults, non-attendance has been found to be associated with younger patients attending a rheumatology clinic (Milne, Kearns, & Harrison, 2014), receiving treatment for alcohol problems (Gudjonsson et al., 2004) but with older patients in cardiology (Cooper, Lloyd, Weinman, & Jackson, 1999). However, in children's services the age of a parent does not seem to have been considered.

Practical barriers: When researchers ask adults why they were unable to attend an appointment the most frequently stated reasons include trouble getting time off work, oversleeping and transportation. This has been reported in adult psychiatry, (Mitchell & Selmes, 2007) adult general practice (George & Rubin, 2003), paediatric primary care (Samuels et al., 2015), paediatric MH (Kazdin, Holland, Crowley, & Breton, 1997) and in a Canadian neonatal follow up program (Ballantyne, Benzies, Rosenbaum, & Lodha, 2015). Greater distances from a clinic have also been shown to predict non-attendance (Gordon, Antshel, Lewandowski, & Seigers 2010). In a study of attendance to MH appointments in Ireland parents' (22.7%) indicated that their child refused to go to an appointment, which, from their perspective, was a practical barrier to non-attendance (Doherty & McCarthy, 2010). Similarly, in an early intervention for young children with ASD and their parents, an effect of treatment condition on attendance was found, with higher rates of missed appointments observed in

group-based parent education sessions in clinic than to home-based individual parent mediated intervention (Carr et al., 2015).

Parent: The mental health (MH) of parents, mothers in particular, also appears to be important in understanding why children miss appointments. Ballantyne et al (2015) qualitative study investigating reasons for non-attendance to a neonatal follow up program, suggested that mothers who felt alone, unsupported and overwhelmed, were less likely to attend. Similarly early dropout, was predicted by higher maternal self-rated internalising symptoms, along with the credibility of treatment in a Norwegian RCT of Cognitive Behavioural Therapy (CBT) for child anxiety problems (Wergeland et al., 2015). A self-reported history of depression in mothers was also found to be the main predictor of missed appointments for psychiatric therapy for children (Gordon et al., 2010). Both studies included some older children who could potentially take themselves to treatment (3-15 and 3-17 years respectively) and, as child age was not accounted for, it is unclear if the results are purely related to parental non-attendance. However, in Wergeland and colleague's study (2015) higher rates of dropout were observed in the youngest age group. Parental psychopathology has also been found to be associated with reduced attendance (Nock & Ferriter, 2005), although none of these studies suggested formal MH diagnoses in the parents was a factor.

Forgetting and confusion over the date have also been identified as the most frequent explanations by adults for their failure to attend children's MH, psychiatric, general practice and primary care services (George & Rubin, 2003; Kazdin, Holland, Crowley, & Breton, 1997; Mitchell & Selmes, 2007; Samuels et al., 2015).

Parents' beliefs about an intervention can affect rates of attendance, with negative beliefs potentially resulting in parents 'voting with their feet'. In a large study (N=156) of treatment dropout, low parent ratings (and child ratings) of the credibility of an anxiety intervention was shown to predict dropout (Wergeland et al., 2015). It may be that a particular treatment may be perceived as too demanding (Nock & Ferriter, 2005), that it does not match parents beliefs about what a treatment should be or that it does not match parent perceptions of their child's problem. Parents may be weighing up necessity of treatment against their concerns, as has been found in studies of medication adherence (Horne & Weinman, 1999) or have concluded that optimal intensity has been reached. Parents' expectations of treatment may also be influential and have shown negative associations with treatment attendance in a psychotherapy context (Smith, Linnemeyer, Scalise, & Hamilton, 2013), in the management of

paediatric chronic pain (Simons, Logan, Chastain, & Cerullo, 2010) and were also a positive predictor of parents' experiences of barriers to treatment participation (Nock & Kazdin, 2001).

2.2.1.2 Child Factors:

The perceived severity of a child's problem may be important in understanding non-attendance. In child psychiatry twenty three percent of parents who failed to start treatment stated that it was because their child's problem had resolved (Doherty & McCarthy, 2010) and parents themselves have indicated that severity of their child's problem is an important factor (Andrews, Morgan, Addy, & McNeish, 1990). In contrast, parent rated severity of child problems was not associated with failure to attend their first appointment in another study (Harrison, McKay, & Bannon, 2004). Child diagnosis may also be relevant, although the underlying mechanism is unclear. In a study of children with a range of diagnoses including ADHD, ODD, conduct, anxiety, mood and autism spectrum disorders, lower DNA rates were observed in children (3-13 years) with an anxiety diagnosis (Gordon et al., 2010). The presence of multiple diagnoses has also been identified as a predictor of drop out (Kazdin, 1996).

2.2.1.3 Service-related:

Factors related to missed appointments include referral source, waiting times, and credibility of intervention. Referral source may be related to parent perceptions of child severity or their child's need for intervention. Of parents who did not attend an initial MH appointment because they considered the referral unnecessary, most (71%) were referred by their child's school (Doherty & McCarthy, 2010). Similarly, referrals where children were mandated to attend, was reported as a predictor of non-attendance in a rural community health centre with the largest effect size (along with waiting time, and minority status) (Sherman et al 2009). The impact of waiting times on attendance has been shown to include both the time between referral and assessment and between assessment and treatment (Curran et al., 2015). As wait time increases so does the rate of DNA. Some DNA's may also be the result of administrative errors (Arai et al., 2014).

In therapeutic interventions, problems with treatment may also be related to the relationship with the therapist. For example helpfulness of a clinician (Mitchell & Selmes, 2007) and problems with clinicians (Doherty & McCarthy, 2010) have both been cited as relating to non-

attendance by patients. Satisfaction with an intervention may be considered a proxy measure of both treatment and clinician factors. In a small study (n=32) comparing ADHD treatments lower satisfaction was reported in those who dropped out. The measure of satisfaction included therapist and treatment factors such as poorer communication by a clinician and treatment organisation (Luk et al., 2001). In SLT establishing and maintaining a good relationship with a client is acknowledged to be central and essential to practice by both the US and UK professional bodies and by SLTherapists themselves (Ebert & Kohnert, 2010).

Summary: In each of the studies reported, multiple predictors of attendance were found and in varying combinations. The relationship between each identified factor and engagement was also inconsistent across studies. What predicts attendance may differ based on the sample under study, the treatment, the definition of attendance used and at what phase of intervention it is measured at. However, we can be confident that the risk factors to reduced attendance to child treatment include demographic factors, practical barriers, severity of child problem, poor maternal MH, negative views or disagreement with the recommended treatment and less than optimal relationship with a clinician.

2.3 Adherence

Definition Adherence can be defined as the extent to which a person's (e.g. a parent's) behaviour corresponds with recommendations by a health professional (e.g. a SLTherapist) (World Health Organisation (WHO), 2003). Terms such as adherence, compliance, persistence and concordance have been used interchangeably across the literature (Barbosa, Balp, Kulich, Germain, & Rofail, 2012). Adherence is the preferred term here as it aims to capture the active involvement of a patient, that is, the treatment should be mutually acceptable and reflecting the concept of informed consent. These are all important in producing a desirable outcome for both patient and practitioner (Aronson 2007). Attempts have also been made to broaden the concept to reflect the dynamic nature of adherence to acknowledge the different phases of adherence during an intervention cycle (Gearing, Townsend, MacKenzie, & Charach, 2011; Geffken, Keeley, Kellison, Storch, & Rodrigue, 2006). Recognition of the triadic relationship between carer-child-clinician is also important in parent-mediated interventions for young children such as SLT (De Civita & Dobkin, 2004).

Measurement: The measurement of adherence varies across the literature with many scales designed for specific studies (Haine-Schlagel & Walsh, 2015). Both objective and subjective approaches have been used with the recommended practice to utilise both (Haine-Schlagel & Walsh, 2015). Objective measures are more feasible in some contexts such as studies of medication adherence whereas in treatments involving behaviour change, subjective measures are the most frequently used (DiMatteo, 2004). This can be a limitation as the concordance between self-report measures and objective scales is low (Garber, Nau, Erickson, Aikens, & Lawrence, 2004) and non-adherence underestimated (DiMatteo, 2004). In family MH treatments both global and specific scales, such as relating to all or certain behaviours, have been used. The most commonly reported is homework completion, using either a binary scale or averages (Haine-Schlagel & Walsh, 2015). Informants of adherence have also varied, including patients, carers, and clinicians, as has the data collection time points (Kahana, Rohan, Allison, Frazier, & Drotar, 2013). In their review of adherence to anti-retroviral treatments Kahana et al (2013) indicated that the most frequent time points for obtaining adherence data was in the past month or 2-4 days. The inconsistency of the measurement of this construct has been widely acknowledged and, despite many recommendations, remains unresolved.

Rates: The World Health Organisation (WHO) reported a universal non-adherence rate to treatment of between thirty and fifty percent (WHO, 2003). In a large meta-analysis of studies

of medication adherence, rates of non-adherence were shown to be higher in larger studies of adherence to medically prescribed treatments, in those focused on an adult population and where recommendations involved behaviour change as opposed to taking medications (DiMatteo, 2004). Parental adherence to ASD interventions with their children has also been found to be higher where medications were involved as opposed to expecting behavioural change (Hock, Kinsman, & Ortaglia, 2014; Moore & Symons, 2009). A fifty percent non-adherence rate has been found in patients taking self-administered prescribed medications (Haynes, Ackloo, Sahota, McDonald, & Yao, 2008), and also in parental adherence to recommendations (medical & behavioural) for children with psychological problems (Geffken, Keeley, Kellison, Storch, & Rodrigue, 2006; Haine-Schlagel & Walsh, 2015). Lower rates have also been reported, for example in parental rates of non-adherence to behavioural treatments for ASD (24%)(Moore & Symons, 2009), in paediatric psychological treatments (30%)(Dreyer, O'Laughlin, Moore, & Milam, 2010), in children's chest physiotherapy (37%)(Goodfellow et al., 2015) and asthma treatment (39%)(DeMore, Adams, Wilson, & Hogan, 2005).

An extensive search of the literature found one small study (n=32) reporting levels of adherence by parents to a parent-mediated paediatric SLT intervention. The authors reported a non-adherence to recommendations rate of thirty one percent. Parents were classified as adherent if they had carried out as little as 50% of the prescribed assignments, which may suggest a high tolerance level in comparison to other studies (Girolametto et al., 1993). Although this rate is comparable to other clinical areas involving parents, adjusting how adherence was defined may have altered rates of non-adherence. One further study, involving contributions from, but not specific to SLT, considered recommendations for children with a cleft palate and cited non-adherence rates of between zero and forty two percent (Paynter, Wilson, & Jordan, 1993). Regardless of the condition, non-adherence appears to be a common factor where patients are required to engage in some form of home-based practice, suggesting that similar non-adherence rates may be anticipated in SLT interventions.

Impact: Non-adherence is related to poorer outcome in a range of clinical services including taking medication (e.g. Mann, Ponieman, Leventhal, & Halm, 2009); adherence to physiotherapy exercises (e.g. Fritz, Cleland, & Brennan, 2007); treatment adherence of patients with swallowing problems (e.g. Low, Wyles, Wilkinson, & Sainsbury, 2001) adherence to treatments for psychological problems (e.g. Geffken et al., 2006) and for parent training programmes for children with externalising behaviours (e.g. Kling, Forster, Sundell, & Melin, 2010). Treatment non-adherence is considered to be a significant cause of intervention failure

across psychological and psychiatric childhood conditions (Geffken, et al., 2006). It remains unknown whether this is the case for paediatric SLT as the only located study incorporating parental adherence in paediatric SLT did not explore the adherence-outcome relationship (Girolametto et al., 1993).

2.3.1 Predictors of Adherence:

Across the literature multiple factors have been reported to influence patient adherence. Ambiguity exists and conclusions limited by measurement issues. In addition, where effect sizes are reported, typically only modest relationships with adherence are identified. In a recent review of systematic reviews of adherence to treatments for chronic medical conditions 771 predictors were identified and those with consistent relationships were classified into five broad groups (Kardas, Lewek, & Matyjasczyk, 2013). These groups were similar to those that predicted attendance (see previous section) and include socio-economic, service related (clinician and system), patient, condition and treatment related factors (Kardas et al., 2013). Of the fifty one systematic reviews included none specified parents as the patient group, only four were specifically related to children with a further eight referring to both children and adults; the majority did not report the patient group in question. For parent participation specifically, one review was located and reported on twenty eight studies of adherence in the MH domain (Haine-Schlagel & Walsh, 2015). Their groupings of predictors also appeared commensurate (child, parent/family, provider and service) suggesting that these broad groupings appear relevant for understanding parental adherence for other conditions.

2.3.1.1 Patient/family-related factors

Socio-demographic: The relationship between indices of deprivation and adherence appear equivocal. Some studies have reported negative associations of measures of SES, such as income and educational levels, with adherence (e.g. Brownbridge & Fielding, 1994; Carr et al., 2015; Haine-Schlagel & Walsh, 2015), and with others identifying it as a predictive factor (e.g. Nock & Ferriter, 2005). However, non-significant relationships have also been found (Danko, Brown, Van Schoick, & Budd, 2016; Dreyer et al., 2010) and a large meta-analytic review of adherence indicated that the SES-adherence relationship appears to be stronger in studies of adults than children, although parents were not specifically mentioned (DiMatteo, 2004). The relationship of ethnicity with adherence has also given mixed results (Haine-Schlagel & Walsh,

2015) with some authors suggesting that these findings may be better explained by indices of deprivation (Jin, Sklar, Oh, & Li, 2008). Marital status (Moore & Symons, 2009) and parent age (with younger parents being more adherent) (Haine-Schlagel & Walsh, 2015) have also been implicated in predicting rates of adherence. Despite the mixed results, deprivation is a risk factor for early language delay (Law et al., 2011) and, within an economically and ethnically diverse society, understanding the relationship between socio-demographic factors and adherence in SLT is important.

Practical barriers: Practical barriers from the perspective of a parent include daily inconveniences related to caring for and parenting a child or children, time, competing demands and child resistance. In a review of qualitative studies, carer fatigue was highlighted, resulting from daily battles for parents with their child over treatment (Santer, Ring, Yardley, Geraghty, & Wyke, 2014). Parents also described the challenge of weighing up the needs of their child in relation to their condition, the treatment itself and the barriers experienced in making the best decision for their child (Santer et al., 2014). Parents have identified lack of time as the most frequent barrier to implementing recommendations by a psychologist, and the total number of barriers, was found to independently negatively predict adherence (Dreyer et al., 2010). Conversely a higher number of daily parenting challenges predicted higher levels of adherence in a group parent education intervention for ASD but only when their child was low functioning (Carr et al., 2015). Some barriers may therefore serve as a motivator for greater participation. The influence of the type of barrier may be important in, particularly when it bears relation to what is targeted by an intervention. In Carr and colleagues' (2015) study intervention targeted joint attention and engagement as well as developing child play, and the challenges described by parents such as children demanding constant attention, interrupting or being constantly underfoot may have been perceived differently following intervention. Equally the intervention may have actually reduced some of these barriers.

Parents: The magnitude of parenting stress and parent psychopathology is linked to non-adherence (Brownbridge & Fielding, 1994; DeMore et al., 2005; Marhefka, Tepper, Brown, & Farley, 2006; Nock & Ferriter, 2005); although in one study, this relationship was non-significant when the number of barriers a parent was facing was taken into account (Dreyer et al., 2010). Parental adjustment, such as coping on adherence, has received less attention in the literature, although that patients in receipt of good social support are better adherers (Jin et al., 2008) may lend some support to this idea.

Aspects of parenting ability may be associated with adherence since, for example, parents with poor child discipline practices showed greater resistance to a parent training intervention for children with conduct problems (Stoolmiller, Duncan, Bank, & Patterson, 1993). Low self-efficacy to follow recommendations has shown to be associated with poorer adherence in a systematic review of adult patients receiving outpatient musculoskeletal physiotherapy (Jack, McLean, Moffett, & Gardiner, 2010) and suggested in a review of parental adherence to child psychological treatment (Geffken et al., 2006). In a study of parental contributions to the management of their child's dermatitis, self-efficacy also emerged as a likely mediator for observed relationships between both child behaviour and parents' education, and self-reported task performance (Mitchell & Fraser, 2014; Mitchell, Fraser, Ramsbotham, Morawska, & Yates, 2015). Self-efficacy is also more important when interventions are aimed at behaviours involving lifestyle changes (Horne & Weinman, 1998). In SLT for young children, parents are often required to make behavioural changes such as modifying their own language; it therefore appears feasible that self-efficacy will be relevant to adherence in this population.

2.3.1.2 Child Factors:

Child factors, including severity and the presence of additional or behavioural problems, may also be pertinent, although again findings are mixed (Cohen, Lumley, Naar-King, Partridge, & Cakan, 2004; DeMore et al., 2005; MacNaughton & Rodrigue, 2001). In some studies perceived severity appears to be of greater importance in relation to adherence than objective indicators of severity (DiMatteo, Haskard, & Williams, 2007; Geffken et al., 2006). In treatments for ASD, severity of symptoms showed a positive association with non-adherence to alternative interventions (Hock et al., 2014) as has low IQ (Carr et al., 2015). Diagnosis has also been implicated; Moore & Symons (2009) found that children with a diagnosis of Autism showed higher levels of adherence than those with Asperger's Syndrome (AS). It is possible that diagnosis may be a proxy for perceived severity as experience suggests that symptom severity in AS is commonly less than in Autism. The relationship between reduced adherence and increased severity may be one of cause and effect with severity serving as a barrier to implementing change.

2.3.1.3 Service related:

Rates of adherence differ according to the type of treatment. This may relate to patients beliefs about the relevancy of an intervention or a judgement on the burden of treatment in the face of other life demands. Within treatment, adherence may also be differentially related to the type of recommendation made (Dreyer et al., 2010; MacNaughton & Rodrigue, 2001) and treatment (Hock et al., 2014). Hock and colleagues (2015) in their questionnaire study of parents of children with ASD (N=273) receiving a range of autism treatments (medical, behavioural, developmental, alternative), found that self-reported adherence was highest for medication treatment. In parent-mediated autism interventions, treatment type and site were found to be a significant predictor of adherence (along with barriers and child non-verbal IQ) (Carr et al., 2015). Balancing treatment demands with child and family needs is not an uncommon decision faced by parents (Santer et al., 2014). Treatment beliefs may also be informed by patient or parent knowledge of the success of particular interventions (Geffken et al., 2006) and their expectations of treatment (Nock & Kazdin, 2001).

A positive relationship with the treating clinician is reported to support better engagement with treatment in children (Santer et al., 2014) and is considered to be a strong factor in some reviews for patients with medical conditions (e.g. Jin et al., 2008). A descriptive review of studies of medication adherence reported consistent relationships between treatment satisfaction and adherence with associations across a wide variety of disease types and study designs (clinic trials/observational studies)(Barbosa et al., 2012).

Conclusion

Both attendance and adherence are required in understanding the influences of participation in SLT. A review of the literature suggests similarities both in the limitations of measuring these constructs and in what predicts engagement, albeit with different emphasis. Current research suggests that socio-demographic factors are more prominent in predicting attendance than adherence and, where attendance and adherence have been directly compared in the same study, SES is a predictor of attendance but not adherence (Carr et al., 2015). Equally patient/parent characteristics have a greater presence in studies of adherence than attendance; however, this may be a feature of omission rather than representing a stronger associations. The sheer number of factors found to be associated with participation reveals the complexity of the issue but simply identifying factors does not explain why an individual participates in a therapeutic intervention. Neither does it provide sufficient evidence to support the development of interventions to minimise the impact of the non-participation. A number of theoretical models have been proposed that aim to address these limitations and will be the focus of the next Chapter.

CHAPTER 3

3. Theoretical models associated with participation

Overview of Chapter

This Chapter focuses on five models assessed to be relevant to the study of participation in SLT following the literature review on attendance and adherence in the preceding Chapter. Two are Social Cognition Models of health behaviour; one reflects the therapeutic alliance in interventions; and the fourth describes the influence of multiple burdens on an individual ability to participate. The most recent framework, aims to unify all previous models. The models are discussed and interpreted in relation to their applicability to parents of children with SLCN.

Relevant literature was obtained from four databases (Embase, Medline, PsychInfo, CINHAL) following the same approach as Chapter 2 (see p. 27) using search terms referring to: 1. attendance/drop-out/missed appointments, 2. adherence/compliance/persistence/concordance/homework completion; 3. engagement/participation. Additional search terms included 'models/frameworks/theory' and subsequently, on identification of preferred models: 'illness perceptions/beliefs', 'self-efficacy'; 'therapist/patient relationship/therapeutic alliance/working alliance'; 'treatment barriers'. As per chapter 2, there were no restrictions applied as to the year of publication and priority given to highest quality research unless in a niche or under-researched area.

3.1 Introduction

Multiple models of health related behaviour have been proposed to understand the psychological and social influences on treatment participation. These models have been reviewed (e.g. Armitage & Conner, 2000; Leventhal, Phillips, & Burns, 2016) and applied to specific diseases (e.g. Harvey & Lawson, 2009; Munro, Lewin, Swart, & Volmink, 2007). Models include those that are focused on e.g. the motivational phase in producing a behaviour, the enactment phase or are multi-stage such as the Health Action Process Approach (Schwarzer, 2008). Certain models may be more suited to particular health conditions especially given the variations in the type of health behaviours (e.g. taking a medicine versus performing an exercise) (Munro et al., 2007). Empirical testing of the validity of models is limited and attempts made to compare models appear to be comparisons of measures rather than the model itself (Jackson, Eliasson, Barber, & Weinman, 2014).

The drive to understand what fosters adequate engagement in treatment is to promote it in individuals where participation is less than optimal. Many factors such as SES and ethnicity are unmodifiable through treatment. Variables that are amenable to change (e.g. beliefs and emotions), and which are thought to mediate the relationship between these socio-demographic factors and intervention participation have been investigated. Paradigms, collectively known as social cognition models, have been proposed that suggest that health, illness and treatment cognitions combine in certain ways to drive health-related behaviours. The basis of most of these models is self-regulation:

“... mental and behavioral processes by which people enact their self-conceptions, revise their behavior, or alter the environment so as to bring about outcomes in line with their self-perceptions and personal goals” (Fiske & Taylor, 1991, p. 181).

The focus of the present study largely relates to the motivational phase of behaviour. Models such as the Health Belief Model or the Theory of Planned Behaviour have reduced applicability as they do not account for environmental or economic factors; or at the level of the individual, the influence of emotions or other factors that may enhance or inhibit behaviour. In contrast Leventhal’s Self-Regulation Model (SRM) does incorporate these factors, including treatment beliefs and the influence of self-efficacy, and has been shown to be applicable to adults and adolescents with physical (Hagger & Orbell, 2003; Law, Tolgyesi, & Howard, 2014) and mental health (MH) problems (Baines & Wittkowski, 2013). Its applicability to the perceptions of

parents, carers and professionals is less clear. In Baines and Wittkowski's (2013) systematic review of the SRM and MH, of the initial search of 3,027 articles (on physical health and illness perceptions), only five were 'other people' related. In addition to the SRM, Social Cognition Theory (SCT) (Albert Bandura, 1991), with its emphasis on self-efficacy, offers an important contribution to understanding the influence of individual characteristics.

Other risk factors for non-participation indicate that 'Therapeutic Alliance' (TA) and 'Barriers to Treatment Participation' (BTP) models may be relevant. A further framework, the most recent (and not published during the design phases of this thesis) is also presented. This is perhaps the most comprehensive, aiming to unify all previous models to explain health-related behaviour change: COM – B (Jackson et al., 2014; Michie, van Stralen, & West, 2011).

3.2 Social Cognition models of Health behaviour

Two models: Leventhal's Self-regulation model and Bandura's social cognitive model and are discussed in detail below.

Leventhal's Self-Regulation Model (SRM) (Leventhal, Diefenbach, & Leventhal, 1992)

The SRM model (Figure 3-1) suggests that patients are active problem solvers who develop a pattern of beliefs when managing their illness. It reflects the dynamic nature of people's beliefs, with individuals re-evaluating their actions on the basis of experience. These dynamic representations of illness directly influence coping behaviour and emotional response, and have an impact on adherence (Petrie & Weinman, 2006). Illness cognitions are stimulated through the perception of symptoms and/or social messages, causing an individual to initiate a search for meaning, evaluate the health threat and consider the question 'am I sick or not?'. Emotional responses run in parallel and these illness schemas and motivate a coping response resulting in active or avoidant behaviours. Self-regulation occurs through the continual appraisal of a copy strategy's effect on perceived symptoms and/or the person's emotions.

The way patients structure their Illness perceptions is consistent and typically includes the following components: identity (name and symptoms), cause, duration of the illness, the degree of control (personal and treatment) over the illness, and perceptions of the impact or consequences on the individual and/or family (Weinman, Petrie, Moss-morris, & Horne, 1996).

These representations may also lead to changes in perceptions of competence and ability to function through self-efficacy and control (behaviour component of model) and/or optimism/disengagement (emotional component of model) (Leventhal, Weinman, Leventhal, & Phillips, 2008). The SRM has also been extended to incorporate treatment beliefs which are influenced by illness beliefs to influence choice of coping strategy e.g. adherence (Horne et al 2004). In medication treatments, patients' beliefs about the necessity of the intervention and concerns about the treatment are influential (Horne & Weinman, 1999). A 'greater necessity belief' has been associated with improved medication adherence and a 'higher degree of concern' about a medicine with lower adherence (Horne & Weinman, 1999).

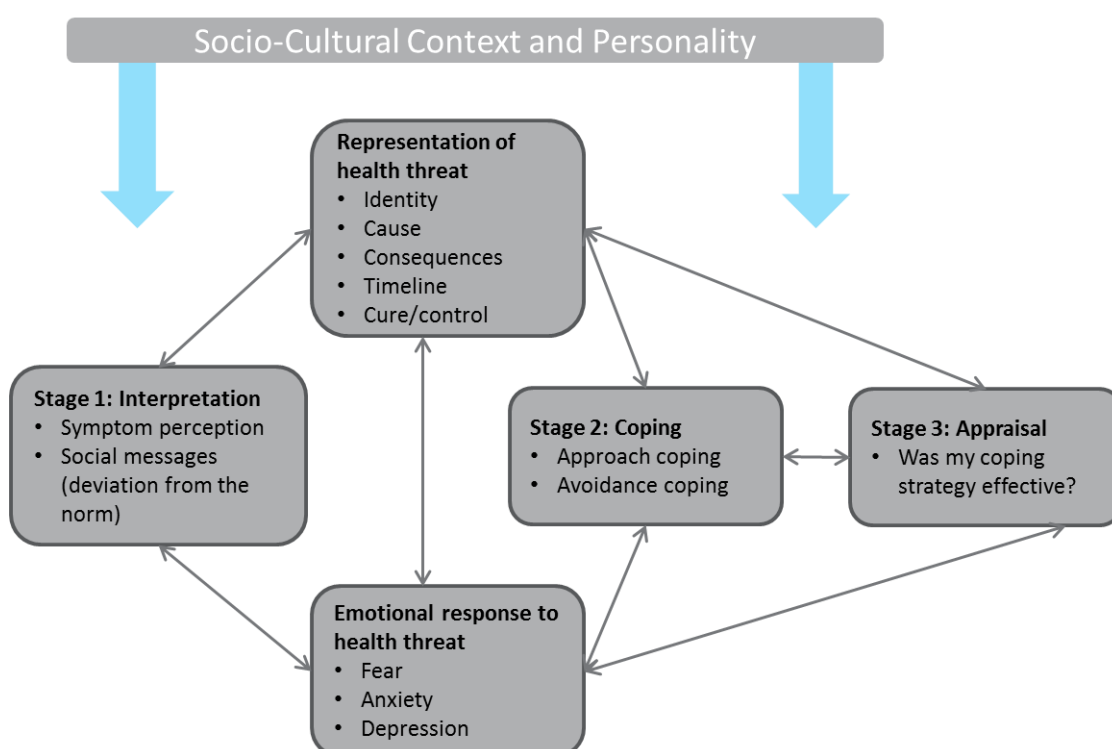


Figure 3-1 The Self-Regulatory Model (adapted from Ogden 2004)

In the present study, the 'individuals' are parents of children with SLCN rather than patients and it is their child's condition they are responding to. Although SLCN are not illnesses per se, they represent a condition requiring treatment. Self-regulation is relevant and parents may employ these strategies to support regulation of their young child. A parent may observe that their child is failing to develop communication, through comparison with siblings or other children. In some cases, a parent may not have recognised these 'symptoms' as a problem, but are influenced through social means following comments from family members or peers. A parent may initially respond through active coping strategies such as locating online resources and helping themselves (Marshall et al., 2007) or respond with avoidant methods such as

'doing nothing' and expecting that their child will develop in their own time. Self-appraisal of their actions will prompt a re-evaluation of their health cognitions and strategy and perhaps result in seeking professional help. These cognitions will continue to be evaluated over the course of treatment and, through a parents approach to coping, may affect participation.

The coherence of an individual's illness scheme may be important in understanding treatment participation (Moss-Morris et al., 2002). The SRM posits that coherence occurs when illness and treatment representations are matched and the intervention is perceived to be effective i.e. when the outcome matches expectations. From the perspective of the individual these schema are coherent, common sense and the coping strategy is also perceived to be logical, even if inaccurate medically or therapeutically. Misconceptions can arise from irrelevant past experiences or social myths which become self-fulfilling because they are confirmed by self-evaluations that are inherently biased. A qualitative study of parent experience of a stuttering intervention in SLT suggested parents' experience of treatment is influenced by how they make sense of treatment and how it might fit with their own beliefs (Hayhow, 2009).

SLT interventions involve multiple recommendations over time and, in young children, include strategies that require parents to change their communication style; in this sense they are making behavioural changes. A SLTherapist may support them to initiate the behaviour required but the parent themselves will need to take responsibility for implementing and maintaining these new behaviours until they become automatic. Individuals who achieve this habitual adherence need to plan, organise and create routines in order to maintain behaviours (Leventhal et al., 2016) suggesting that a degree of competency in executive functioning would be required.

For coherence to occur in treatment, a match between the therapist and patient (or parent) cognitions is also important. Patients' own representations of their illness are unique and are often at variance with their healthcare professional's view (Brooks, Rowley, Broadbent, & Petrie, 2012), however, this is not usually explored during a consultation (Petrie, Jago, & Devcich, 2007) even though recommended in SLT (Carroll 2010). Differing beliefs between parents and SLTherapists have also been reported, relating to beliefs about language development, the causes of language delay, and what constitutes effective intervention (Marshall et al., 2007). Some studies have also identified cultural differences in parent representations of language development (Johnston & Wong, 2002), causes of SLCN, and how parents communicate with their children (Rodriguez & Olswang, 2003; Simmons & Johnston,

2007). Current interventions in SLT are typically based on research in families of Anglo-American/Euro-Canadian descent, which may conflict with beliefs about intervention (Simmons & Johnston, 2007). Culture is increasingly recognised as relevant in service provision, with British culture becoming more ethnically diverse (of National Statistics 2011). Self-regulation theory is applicable across cultures, particularly influencing causal beliefs (Diefenbach & Leventhal, 1996; Garro, 2000). Factors such as the heritability of SLCN and the difficulties in identification of transient versus persistent SLCN may also affect a parent's perception of their child's problem.

Illness perceptions are associated with treatment adherence in a number of disease types including asthma (e.g. Horne & Weinman, 2002a), acute myocardial infarction (French, Cooper, & Weinman, 2006), epilepsy (Jones, Butler, Thomas, Peveler, & Prevett, 2006), cystic fibrosis (Bucks et al., 2009) and MH disorders (Aujla et al., 2016). However, significant predictive relationships have not always been found and effect sizes tend to be small (Aujla et al., 2016). The majority of studies are focused on patient perceptions but parent perceptions have been considered in the case of childhood autism (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010; Dardennes et al., 2011), in anorexia nervosa (Sim & Matthews, 2013), in asthma (Nowack, Tuite, Holt, & Hoffman, 2010), cystic fibrosis (Beinke, O'Callaghan, Morrissey, & Duregger, 2016) high risk neonatal infants (Brooks et al., 2012) and in children receiving physiotherapy (Rabino, Peretz, Kastel-Deutch, & Tirosh, 2013), although typically related to psychological adjustment, or emotional response, rather than adherence to treatment specifically.

Studies of patients in both the physical and mental health domains have evaluated the contribution of specific beliefs within the structure of an illness schema to, for example, adherence, coping and choice of treatment, with a number of helpful systematic reviews. Hagger and Orbell's review (2003) included forty five studies representing twenty three physical illnesses and examined the relationships between illness beliefs and seven types of coping behaviours as well as to health outcomes. Despite the heterogeneity of illness types, beliefs were considered homogenous across approximately fifty per cent of the studies. Findings indicated that a greater belief in the controllability of an illness (control/cure belief) was associated with active attempts to deal with the problem including adherence. Other positive associations were with positive reappraisals such as personal growth and acceptance and seeking social support. In contrast a belief in the serious consequences of a condition and the high level of symptom recognition were associated with an avoidant coping response,

expressing negative emotions and frequency of doctors' visits. Believing that their condition would last a long time was also associated with positive reappraisal but also with avoidance or denial.

A recent review, focusing on self-management of both acute and chronic medical conditions, concluded that illness perceptions did not predict adherence (Aujla et al., 2016). This paper included a meta-analysis (21 studies) and a descriptive review (31 studies) with findings from both showing agreement. In this review illness cognitions only showed weak associations with adherence and heterogeneity was demonstrated across most beliefs with the exception of coherence. The strongest relationships included the domains of *identity*, *timeline acute/chronic*, *consequences*, *personal control*, *treatment control*, *cure/control*, *illness coherence* (with effect sizes between .04 and .13). *Timeline cyclical*, *emotional representations* and *causal beliefs* and associations with self-management behaviours, did not reach significance. The majority of included studies examined attendance or medication adherence with fewer (28%) relating to more complex behaviours such as dietary or physical activity, reducing its relevance to this study.

The literature relating to the management of MH conditions include both medication and behavioural treatments, and is more informative in the present context. A systematic review of illness perceptions in MH indicated that adults who perceived their problem as chronic, controllable but with negative consequences engaged in active coping and help seeking behaviours (Baines & Wittkowski, 2013). A belief that treatment could control the condition was positively associated with treatment adherence, although the authors acknowledged that demographic factors such as age may have a role. Coherence was important in seeking help and engaging in treatment in studies of both adults and adolescents. Perceived severity of the problem was associated with lower control, a stronger illness identity and greater levels anxiety and depression. These findings appear comparable to those in physical health.

Of the few papers that have looked specifically at parent beliefs, only two considered their relationship to adherence. In babies (N=65) with torticollis, parents beliefs about the consequences of the condition on their child, both current and future, along with parent perception of the importance of the intervention, predicted adherence to physiotherapy (Rabino et al., 2013). The second study, related to childhood asthma, indicated that a high proportion of parents were concerned about the side effects of medication and identified it as a barrier to adherence (Nowack et al., 2010).

Other papers examined the relationship between illness perceptions and treatment choice with one study (N=89) considering this relationship in autism (Dardennes et al., 2011). These authors reported that parents who believed in an early traumatic cause were less likely to be using behavioural interventions to support spontaneous communication in children. Also, parents were more likely to be using medication when illness during pregnancy was identified as a cause, and if food allergies were considered causal parents were more likely to be using vitamins and special diets but less likely to be using pharmacology. A further paper, based on the same cohort, reported that parent ratings of the seriousness of condition was positively associated with use of education approaches; a belief in an unpredictable course of the disorder was associated with medication use; a sense of personal control was negatively associated with the use of nutritional or medical treatments; and attending training programmes was associated with stronger hereditary beliefs (Al Anbar et al., 2010). These two studies were exploratory in nature, with the results requiring confirmation. Specific causal beliefs have also been found to influence treatment preference in adult patients. For example, if a condition is believed to be genetic then patients appear to prefer medication as opposed to behavioural intervention such as making lifestyle changes (Leventhal et al., 2008). Treatment beliefs maybe more strongly related to adherence than illness perceptions as they are focused on the response stage and how a person deals with a problem (Leventhal et al., 2008).

When parents hold negative views of their child's condition it can have an impact on the child, the parent themselves and the family as a whole and potentially result in an avoidant style of coping. In a small study (N=25) of adolescents with anorexia nervosa and their mothers, poorer personal and family functioning was observed in mothers who considered their child's condition to be severe, chronic, uncontrollable, with a high emotional burden and who had a reduced understanding of the condition (Sim & Matthews, 2013). These mothers were less satisfied and less confident as parents, worried more and were more likely to report depressive symptoms in themselves and reduced family cohesion (Sim & Matthews, 2013). Similarly in mothers of children with cystic fibrosis, belief in the cyclical nature of the condition was significantly associated with maternal distress (Beinke et al., 2016), with the emotional representations associated with the disorder being the main predictor of distress. In mothers of high-risk newborns, beliefs of a longer timeline, the consequences and the seriousness of their child's condition along with a reduced understanding of the problem, were strongly

related to maternal stress. In addition maternal perception of severity, rather than objective measures of severity was also strongly associated with stress (Brooks et al., 2012).

For parents of children with a health condition, beliefs about cause, consequences, control/cure, treatment beliefs, cyclical timeline and coherence variously influence coping strategies such as adherence to treatment, and treatment choice. These findings bear similarities with those of patients themselves and suggest that the SRM has potential in understanding participation in SLT.

Bandura's Social Cognitive Theory (Bandura, 1991)

Bandura's Social Cognitive Theory aims to explain how an individual acquires and maintains certain patterns of behaviour. This theory of self-regulation states that the behaviour of a person is shaped and influenced by both personal and environmental factors: 'reciprocal determinism' (see Figure 3.2). Individuals have beliefs about what they are capable of, they anticipate consequences, set goals, and formulate action plans in order to achieve a certain outcome. Through thinking ahead people motivate themselves towards desired outcomes. Two types of efficacy beliefs are core to this model: self-efficacy and outcome efficacy. Outcome efficacy refers to the confidence an individual has in that the action plan will achieve the desired effect. High outcome expectations are not necessarily required in order for self-efficacy to be enacted, although the combined effect of self-efficacy and outcome expectations is greater (Iannotti et al., 2006).

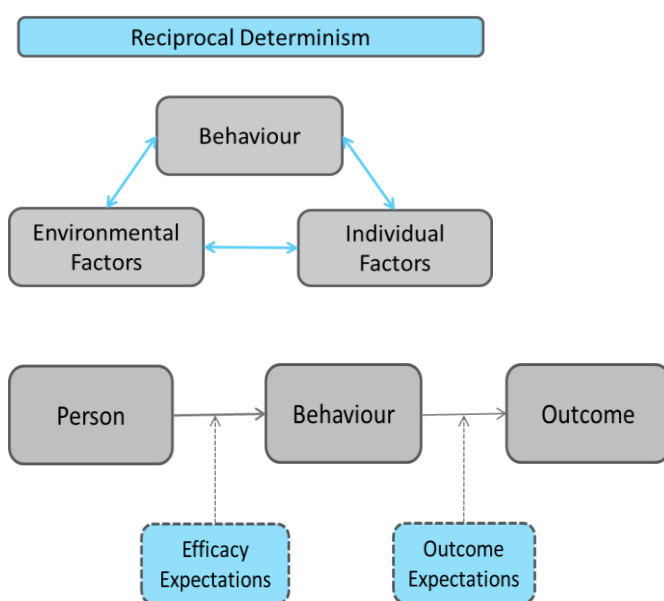


Figure 3-2 Social Cognitive Theory (Bandura 1991)

Self-efficacy, a person's confidence in performing a task or action, is a major concept in this model. The determinants of SE include individual factors: performance feedback, physiological states (emotional arousal), and environmental factors including vicarious learning (modelling) and verbal persuasion. How efficacious one feels will determine what coping behaviour is initiated, how much effort will be expended and how long it will be sustained (Bandura, 1997). This theory proposes that higher SE will increase motivation across these areas and lead to better performance, although at the planning stage some self-doubt may provide an incentive to acquire the necessary skills and knowledge to perform the task (Bandura & Locke, 2003). However, artificially inflated self-efficacy may result in reduced motivation to prepare and lead to unsuccessful outcomes. With high self-efficacy expectations, individuals set their goal levels higher but then allocate fewer resources to achieving them, resulting in poorer outcomes (Vancouver & Kendall, 2006). Thus the relationship between self-efficacy and non-adherence may not be linear even though there are significant associations between low self-efficacy and non-adherence (Geffken et al., 2006; Jack et al., 2010).

Self-efficacy is domain specific (Bandura, 1978) and two areas may be relevant in SLT. Firstly, a parent's confidence in practising a specific task with their child at home (homework self-efficacy), and secondly, a parent's self-confidence in making changes in their own interaction, play and communication with their child. When parenting self-efficacy was examined in mothers of pre-school children with SLCN, they were found to have generally high self-efficacy beliefs with exceptions in the following domains: discipline, play and teaching (Harty, Alant, & Uys, 2007) which are relevant to SLT intervention. Parenting self-efficacy may, of course, change over the course of an intervention even when not directly targeted (Warren, Brown, Layne, & Nelson, 2011). Family factors may also contribute to self-efficacy, as stress and family functioning are recognised as affecting parenting (Secco et al., 2006).

3.3 Therapeutic Alliance (TA) (Bordin, 1979)

Therapeutic alliance, referring to the relationship between client and therapist and the contractual aspects of planning treatment, has consistently shown a modest relationship with outcome (Elvins & Green, 2008; Shirk & Karver, 2003), with better adherence (Jin et al., 2008; Santer et al., 2014; Thompson & McCabe, 2012) and with some evidence to suggest with reduced risk of dropout (Accurso, Hawley, & Garland, 2013; Doherty & McCarthy, 2010).

SLTherapists view the client-therapist relationship as crucial to successful client outcomes (Carroll, 2010; Ebert & Kohnert, 2010). Although there is overlap with treatment beliefs and the necessity for coherence between clinician and patient as described in the SRM, this theory may offer an additional focus. Bordin (1979) considered that the therapeutic working alliance between a practitioner and patient was one of the key determinants of behaviour change in psychotherapy. With its origins in psychoanalytic theory, TA is structured around three themes: the relationship between therapist and patient: 'bond', agreement on the goals of treatment: 'goals' and agreement on the tasks associated with the intervention: 'task'. It is the aspect of 'bond' that maybe particularly unique in this context as perceptions of treatment are incorporated in the SRM model. These three themes have been maintained by some researchers (e.g. (Horvath & Greenberg, 1989) whereas others have represented them as two concepts: personal alliance and task-related alliance (e.g. Hougaard, 1994).

3.4 Barriers to Treatment Participation model (BTP) (Kazdin, 1996)

This model was originally guided by two general approaches: a risk factor model, identifying preceding conditions that increase the chance of an outcome occurring, and a burden of treatment model which indicates that families can have multiple sources and significant amounts of stress and, of which attending treatment may be additional (Kazdin, 1996). It was developed with specific reference to child psychotherapy and the relevance of parent participation in their child's treatment. Factors that can contribute to family stress include economic deprivation, parent physical or MH problems, parenting stress and severity of child problem. Kazdin (1996) demonstrated that the cumulative effects of multiple burdens was associated with an increased risk of dropping out and more specifically leaving intervention early on in the process. This concept of stress as a burden was further extended to include practical obstacles, relevance of the intervention, demands of treatment and relationship with the therapist in the development of the Barriers to Treatment Participation Scale (BTPS) (Kazdin et al., 1997). Although there is a clear overlap between these ideas and therapeutic alliance, it is the total numbers of barriers which may be of additional interest and the *practical obstacles* and *parent stress* domains are unique to this model. Better TA is associated with fewer barriers, even when accounting for pre-treatment variables such as SES parent psychopathology/stress child dysfunction (Kazdin, Marciano, & Whitley, 2005).

The association between the number of perceived barriers and treatment dropout has been observed in parent training for children referred with externalising behaviour difficulties (Kazdin et al., 1997, Kazdin, 2000), to attendance at paediatric community MH centres (Stevens, Kelleher, Ward-Estes, & Hayes, 2006) and with a systematic review reporting medium to large effect sizes in both efficacy and effectiveness studies (de Haan et al., 2013). A clear dose-response relationship was observed with greater numbers of barriers resulting in a higher likelihood of dropout (Kazdin et al., 1997). Increased barriers have also been shown to be related to outcome and therapeutic change in young people and their families receiving psychotherapy, with moderate effect sizes (Karver, Handelsman, Fields, & Bickman, 2006). In most of these studies children tend to be adolescents but one study, exploring attendance in parents of young children (3-6 years) with externalising behaviour problems in a paediatric primary care setting, found no relationship between barriers and attendance (Lavigne et al., 2010).

Although the main focus of this model is attendance, the concept of barriers impeding action may also be relevant to adherence behaviour. For example, MacNaughton and Rodrigue (2001) examined barriers to specific treatment recommendations. Although the types of barriers were different, they also found that the total number of barriers was the most salient predictor of adherence. Parents of children with SLCN are also likely to experience multiple sources of stress in their lives, both unrelated and related to their child's need and so it is feasible that the premise of this model is applicable to SLT.

3.5 A unifying model COM-B system: capability, opportunity motivation – behaviour (Michie et al., 2011)

As previously alluded to there is considerable overlap in the models discussed, for example beliefs about an intervention are accounted for in Leventhal's model, Therapeutic Alliance, and the Barriers to treatment participation. A unifying model is presented below which may account for potential duplication in concepts.

This model aims to be a comprehensive overarching framework of behaviour and was originally developed to support the design and development of behaviour change interventions. COM-B consists of three factors that were identified as the minimum required to achieve a change in a targeted behaviour: capability, motivation and opportunity (figure

3.3). The model incorporates the reciprocal influence between these components and the behaviour and reflects that both capability and opportunity can affect motivation. Capability is defined as a person's psychological and physical ability to carry out a behaviour. Motivation includes both reflective and automatic mechanisms that drive the will to act, such as conscious decision making and habitual processes, and includes the influence of emotions. Opportunity refers to the environmental factors, both physical and social, that make a behaviour possible. Not all three factors are expected to be required in order to change a behaviour (Michie et al., 2011). This model has been recently applied to medication adherence (see table 3.1) (Jackson et al 2014).

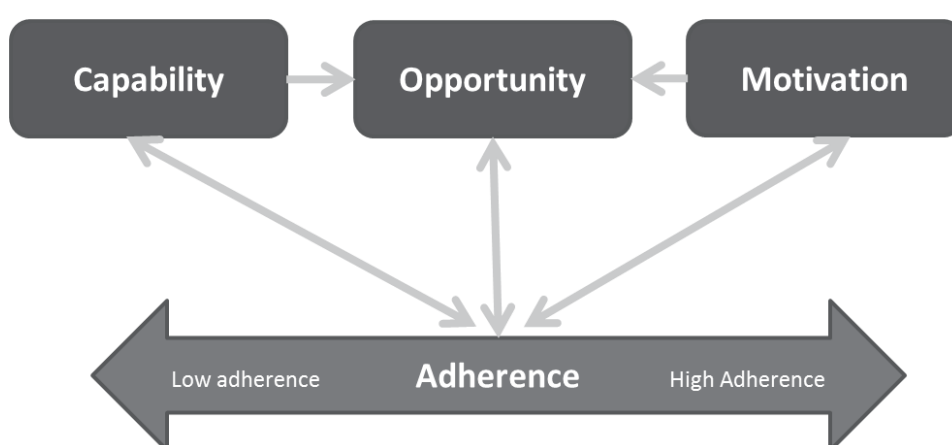


Figure 3-3 COM-B model applied to Adherence (Jackson et al 2014)

In this version adherence (the 'Behaviour') was presented as a continuum, reflecting the different degrees to which an individual might be adherent. The factors previously identified within the literature that are associated with medication non-adherence were mapped under the three domains within COM-B (table 3.1) (Jackson et al., 2014). For example: patients' ability to understand their condition and the treatment has been shown to be associated with adherence and lies within the *Capability* component; patients' perception of the problem, also associated with adherence, lies within the *Motivation* component and patients relationships with a health professional within the *Opportunity* domain. Although specific to medication adherence, the authors also considered this applicable to any type of adherence behaviour.

Table 3-1 Factors associated with medication adherence applied to COM-B (Jackson et al 2014)

Capability	Opportunity	Motivation
<i>Psychological</i>	<i>Physical</i>	<i>Reflective</i>
<ul style="list-style-type: none"> • Understanding of condition and treatment • Cognitive functioning • Executive function 	<ul style="list-style-type: none"> • Cost • Access • Packaging • Physical characteristic of medicine • Regimen complexity • Social support • Relationships with Health professional 	<ul style="list-style-type: none"> • Perceptions of problem • Beliefs about intervention • Outcome expectancies • Self-efficacy
<i>Physical</i>	<i>Social</i>	<i>Automatic</i>
<ul style="list-style-type: none"> • Physical capability to adapt to lifestyle changes • Dexterity 	<ul style="list-style-type: none"> • Stigma, fear of disclosure • Religious/cultural beliefs 	<ul style="list-style-type: none"> • Cues for action • Mood state/disorder

This model has the potential to support not only the design of studies of non-adherence in new areas such as SLT but also in the design of interventions aiming to improve adherence to treatment.

Conclusion

This Chapter discussed five models of health-related behaviour change. Their potential application to the present study and integration with the preceding chapters will be summarised in the following chapter.

CHAPTER 4

4. Literature review: summary and implications for the present study

Overview of Chapter

The literature reviewed in the preceding Chapters will be summarised along with the implications for the design and aims of the present study.

4.1 Summary of SLCN

SLCN represent a broad group of conditions caused by genetic and environmental factors. Conditions overlap and there is significant co-morbidity but also uncertainty about the specificity of definitions of some disorders. It is not uncommon, with approximately six percent of children affected. A proportion of children will have SLCN that resolve spontaneously; however, methods of identifying this group are not in routine use. Clinical services therefore risk providing intervention when none is required and raising unnecessary anxiety within the family. Persisting SLCN can effect social, emotional and educational development with a future impact on employment and an increased risk of offending. The demand on services to meet the needs of this population is significant yet non-attendance is a problem in many services.

SLTherapists are the main professionals providing intervention for children with SLCN; and in young children, shared responsibility with parents for delivering SLT intervention is increasing. The amount of parent involvement can vary, from providing daily parent-child interaction interventions to completing 'homework'. SLTherapists' often provide multiple recommendations which can involve behavioural changes such as altering a parent's communication and interaction style. The rationale for involving a parent is to increase intensity and support generalisation, however, it remains unclear within the SLT profession as to what constitutes adequate intensity, particularly when manualised treatments are modified to meet service demands. The extent to which parents implement these SLT recommendations outside of the clinic is also currently unknown.

SLTherapists have clear intentions to involve parents at all stages of intervention but in practice there are a number of barriers restricting their ability to account for parental preference or capability to participate in a treatment. Failure to address parent preference or capability may affect adherence to treatment or in some cases risk non-attendance. Many qualitative studies have explored parent experience and satisfaction and concluded that parental involvement is a critical factor in achieving optimal participation and outcome but this literature search has not identified any research in SLT that has systematically explored parent factors and how these might influence participation and child outcome.

4.2 Summary of attendance and adherence

Little is known in SLT about parent participation in treatment despite the recognition that non-attendance and non-adherence is a universal problem in healthcare. Attendance and adherence are related but distinct concepts and both are important in achieving efficacious interventions. The literature suggests that we might anticipate a non-attendance rate of between 13-20% and a non-adherence rate of between 20-50%. Multiple predictors of attendance have been identified but with limitations arising from the evaluation of different populations, treatments, definitions and at what phase of intervention it is measured at. It is likely however, that the risk factors for non-attendance will include demographic factors, practical barriers, severity of child problem, poor maternal mental health, negative views or disagreement with the recommended treatment and less than optimal relationship with a clinician. Similar factors appear relevant for predicting non-adherence but potentially with a different emphasis. Socio-demographic factors and practical barriers may be more pertinent for non-attendance whereas characteristics of the patient or parent may be more relevant in adherence.

It is also important to recognise that not all treatment drop-out in SLT should be perceived negatively, as parents may actually be making the best decision for their child and that lower intensity treatments can also be beneficial. The uncertainty about adequate dosage for an individual child also lends weight to this argument. Attempts to predict attendance or adherence to treatment may fail if research does not account for this complexity.

4.3 Summary of theoretical models

The theoretical models described in Chapter 3 provide a method of understanding why an individual might behave in a certain way and provide an opportunity to identify modifiable predictors which mediate unmodifiable ones such as socio-economic status. A number of models have been described including two prominent self-regulation models, Leventhal's Self-Regulation Model (SRM) and Bandura's Social Cognitive Theory (SCT) as well as Therapeutic Alliance model (TA) and the Barriers to Treatment Model (BTM). A further model was also presented, COM-B, which is perhaps the most integrated.

From the SRM perspective, a parent will form a set of beliefs about their child's SLCN and what is needed to resolve the problem that is coherent to them. This will lead to an emotional response and an action in the form of a coping strategy, which will influence attending an appointment or following a recommendation. These representations are dynamic and influenced by personal experience and social influences. The coherence of these beliefs is central and it occurs when illness and treatment representations are matched and when the outcome matches the parent's expectations. When an intervention does not meet their expectations, parents can become resistant to a therapy. It is also important for participation that therapist and parent cognitions are congruent. Differences in parental belief of cause, how language develops, and interventions, have been reported in SLT, including cross cultural differences. This suggests that in SLT non-participation may occur when parents' lack a coherent perspective on their child's problem and intervention and when these beliefs are not congruent with the treating SLTherapist.

The individual beliefs that form the basis of a patients' model of their problem are associated with treatment participation in adult studies of both mental and physical health, albeit with small effect sizes. In parents, the influence of beliefs about their child's problem (e.g. the cause, consequences, control/cure, treatment beliefs, cyclical timeline and understanding of the problem) on coping strategies and treatment choice has been explored indicating that the parental beliefs may influence adherence.

Self-efficacy is central to SCT; this theory supports the notion that higher self-efficacy increases motivation and performance, although at the planning stage some self-doubt may also be helpful. Two self-efficacy domains are relevant to SLT: homework self-efficacy and parenting self-efficacy. SLT interventions in young children often involve enhancing what might be considered parenting skills particularly involving communication, play, teaching and behaviour. We may therefore anticipate that parents who are confident in these areas would be more adherent to SLT.

In SLT the relationship between a therapist and a parent and the notion of parental involvement in both planning and the delivery of an intervention is valued but isn't always achieved. Research has shown that the Therapeutic Alliance is related to both outcome and adherence and would therefore be important to include in the present research.

The BTM model suggests that the number of barriers experienced by a parent both during the course of an intervention and in delivering a specific recommendation may negatively affect their ability to attend appointments and follow recommendations.

Finally the COM-B model indicates that the factors to be explored within the present study fall largely in the *Motivation* domain, including parents' perceptions of their child's problem, views on their child's treatment, self-efficacy and their emotional representations. Parent relationships with SLTherapists falls within the *physical Opportunity* domain; practical barriers to interventions in this study could be included under this domain but also the *physical Capability* domain.

Conclusion

This PhD examines the levels of attendance at SLT appointments and adherence to SLT interventions in young children. It will also investigate the relationships between levels of attendance, adherence and the outcomes for children following intervention. Finally it will consider potential predictors of non-attendance and non-adherence and whether these factors also relate to child outcome. It will be primarily focused on motivational factors to participate in SLT. A focus on parental perspectives at the beginning of their journey may provide a future opportunity to design interventions to increase participation from the outset.

To achieve these aims the PhD has three phases:

The limited knowledge about family participation in SLT intervention with young children indicated the value of a preliminary study with parents using a qualitative methodology to identify relevant factors. Similarly the limited availability of measures specific to this population would indicate the necessity of a pilot study to evaluate the primary outcome measures and to test the psychometric properties of scales developed for this research. Phase 1 is a qualitative interview study with parents to identify factors that affect parent participation in SLT intervention, and to inform the adaptation and selection of measures to be used in subsequent phases. Phase 2 is a pilot study to assess the appropriateness of the main outcome measures and to pilot modified measures for use in phase 3. Phase 3 is a prospective cohort study focused on achieving the main aims as outlined above.

CHAPTER 5

Phase 1: A qualitative study exploring parental experience of speech and language therapy (SLT) in young children with Speech Language Communication Needs (SLCN) to support the understanding of factors associated with parental adherence.

Overview of Chapter

In light of the literature review, this chapter reports on the first empirical study of the thesis, a qualitative study constituting Phase 1 of the research. It begins with a review of the research literature on parental experience of SLT and proceeds to describe the methods and results of the study. Both the collective views of the cohort and observable differences are discussed, concluding with the aims of the final phase of this research.

Ethical and Research and Development approval was obtained for this study (REC reference: 10/H0808/155 Protocol number: CSA/10/036 R and D Reference: RDLam572)

5.1 Literature review: Parent Beliefs and Experience of SLT

5.1.1 Introduction

To gain an in depth understanding of existing knowledge of parent thoughts and experiences of SLT for pre-school children, a literature search of four databases (Embase, Medline, PsychInfo, CINAHL) was conducted using the terms 'parent' AND 'experience' AND/OR 'belief' AND/OR 'views' AND speech AND language AND therapy. This search yielded 187 papers which were screened by the researcher for relevance. Papers were excluded if they did not relate to SLT, did not involve parent perspectives and focused on children over the age of six years; exceptions to the age restriction were studies of older children that included retrospective parent views. Included publications were related to English language SLT services. These criteria resulted in thirteen papers for inclusion in this review, ten were qualitative designs, two quantitative and one mixed. The qualitative studies were predominantly inductive in nature, providing tentative hypotheses and recommendations for SLT practice, but theoretical application was minimal.

What follows is a descriptive review of the included studies, focused on parents of pre-school children receiving SLT. Results of the studies were synthesised taking into account the theoretical basis for this thesis described in Chapter 4 and nine themes were identified. An additional area emerging from the studies focused on describing observed differences in beliefs and experiences between cultures and also parents and professionals.

5.1.2 Responding to the Problem

Across studies parents varied in their approach to recognising and responding to their child's SLCN. In one qualitative study with twenty three parents, the authors were interested in seeking parents' views of the surveillance process that they were involved in. Participants were drawn from a larger sample participating in a RCT (Glogowska & Campbell, 2004). The RCT involved randomisation into immediate SLT treatment or watchful waiting (Glogowska & Campbell, 2000). The children in the RCT were all under three and a half years and had a range of SLCN including language or speech difficulties. Children with a primary diagnosis of dysfluency or dysphonia were excluded. Participants from both arms of the RCT were included in the qualitative study and purposefully selected in order to achieve maximum variation in

perspectives. Parents who declined a referral to SLT services were excluded. Data was analysed thematically using the Framework approach (Ritchie & Lewis 2003). Here many parents were happy to engage in watchful waiting before seeking treatment. This included monitoring progress and helping the child themselves, particularly when there were no overt 'medical' (unspecified) problems. Parents stated that they would subsequently seek help if their child's progress did not meet their expectations. Health visitors were important both in monitoring but also in prompting referrals at routine checks. Parental views were instrumental in the speed at which referrals were made (Glogowska & Campbell, 2004).

In another paper by Glogowska (1998) semi-structured interviews were conducted with sixteen parents. In this, and also the Glogowska & Campbell (2004) study, it was reported that not all parents recognised their child's needs immediately and, for some, awareness emerged through their experience of SLT. Although unclear, the participants in these two papers appear to be separate groups but drawn from the same RCT cohort, given the difference in sample sizes and the different themes that emerged. Delayed recognition is perhaps unsurprising as some difficulties may be less obvious to parents such as problems in understanding language, whereas speech intelligibility difficulties or delays in expressive language may be more visible. For example, in one study all parents considered their child to have no problems in understanding language even though forty three percent had confirmed receptive delays (Kummerer, Lopez-Reyna, & Hughes, 2007) and similarly in another study, only five percent of mothers recalled concerns about their child's receptive language before they attended a language unit. This retrospective study using qualitative methodology was a relatively large study (Rannard, Lyons, & Glenn, 2004). The authors interviewed forty parents whose children (6.10-16.9 years) had previously attended language units in the UK. A life history approach was taken in the interviews and a thematic analysis was undertaken. Many parents recalled their children having severe temper tantrums when they were very young, some of whom expressly thought they were related to their child's SLCN. It was unclear though if it was this behaviour that prompted recognition of the SLCN. Typically it was parents who recognised the problem first, although in others it was the extended family, the nursery staff or a health visitor. Recognition was through comparison with siblings or other children and for a few, the problem was obvious to them without such comparisons. Recognition preceded referral to SLT by as much as two years with many parents describing professionals as barrier to expediting referrals.

Across the studies parents have recognised their child's problems themselves or been influenced by families or professionals or comparisons with other children. It is unclear if the type or visibility of their child's problem influenced recognition.

5.1.3 Causal beliefs

A number of qualitative studies have reported parents' views on the causes of their child's SLCN. Parents have variously considered medical and physical problems, child factors and environmental factors as causal. Medical causes included hearing impairment, (Glogowska, 1998; Kummerer et al., 2007; Marshall et al., 2007), infected tonsils and adenoids, perinatal difficulties and physical problems related to the child's tongue, size of the mouth and vocal cords (Glogowska, 1998). For some, heritability was raised as other family members had experienced similar difficulties (Kummerer et al., 2007). Child factors included their personality and emotional characteristics, preferences of physical activities over listening and learning; being 'lazy' and lacking in confidence (Glogowska 1998). Whether they were male or female was mentioned by some parents with the view that girls talk sooner (Glogowska, 1998; Marshall et al., 2007). Environmental influences included the effect of dummies or bottles on speech, and the influence of siblings, including both positive (siblings provide good language models) and negative views (siblings talk for the child/ no siblings to talk to) (Glogowska, 1998; Marshall et al., 2007).

Not all parents consider the impact of broader illness or disability (Law 2000, Marshall et al 2007). Causal uncertainty and self-blame was common, featuring in three studies (Glogowska, 1998; Langevin, Packman, & Onslow, 2010; Marshall et al., 2007). Some parents stated that the feeling of being stigmatised by their child's SLCN and their desire to make sense of the problem led directly to self-blaming thoughts (Glogowska & Campbell, 2004). Parents blamed themselves for not spending enough time with their child or providing them with insufficient social contact (Glogowska 1998) and considered their child's SLCN to be as a result of their poor parenting (Glogowska & Campbell, 2004).

5.1.4 Emotional responses

How parents felt about their experience of SLT and SLCN was described in two qualitative studies. In the first study, Glogowska and Campbell (2000) interviewed sixteen parents, twelve

mothers, and two couples. As with Glogowska & Campbell (2004) and Glogowska (1998) participants were drawn from the same RCT cohort. Glogowska and Campbell (2000) reported on parents' feelings over the course of SLT, at referral, during intervention and on completion of treatment. Parents described a range of emotional responses to their child's SLCN including both relief and concern at the point of referral, worry about the implications of their child's SLCN and uncertainty about the future, particularly in relation to discharge. Emotional responses were not static for example experiencing a reduction in fear whilst receiving therapy and being provided with reassurance (Glogowska & Campbell, 2000).

The focus of a study by Langevin and colleagues (2010) was parents' perceptions of the impact of stammering. Seventy seven parents of pre-school children completed a survey of their views that provided both qualitative and quantitative data. The nineteen item questionnaire was developed by the authors and included four closed questions pertaining to the impact of stammering on parents, participants were also provided with options to comment descriptively. The authors did not provide any data on the psychometric qualities of the questionnaire, although for the purposes of the present review only one question was of interest. When asked if they were emotionally affected by their child's stammer, 71.4% responded positively. The qualitative analyses indicated that parents in this study experienced frustration and were upset about their child's stammer; they were worried about what to do when their child stammered and some were fearful that they were partly responsible for the stammer. Thirty five percent of the children had additional diagnoses of speech or phonology impairments, although no effect of diagnosis was found (Langevin et al., 2010). From these studies and regardless of the type of SLCN, parents experienced a range of negative emotional responses and, at least for those with speech and stammering difficulties, it is not uncommon.

5.1.5 Beliefs about language development.

Many parents are reported to take language development for granted, that children 'just' learn to talk (Glogowska 1998; Glogowska & Campbell 2004; Law 2000). Other perspectives have been described in the literature. One study compared parental beliefs about language development, language delay and interventions, and compared them with SLTherapists beliefs (Marshall et al., 2007). This research involved fifteen interviews with parents, ten with mothers only, five also included partners; and nine interviews with SLTherapists, seven with one, and two with two therapists. Details about the children was limited to age (>2 years). Descriptions

of the differences between therapist and parents will be discussed later in this review. Parents described the influence of hearing, gender and personality on language development, for example that an introverted child will develop language more slowly. Social experiences were valued in developing child language including those offered by family, siblings, and educational settings such as nursery. Parents highlighted their role in spending time talking to their child to provide opportunities for their child to copy them. Visual media such as TV or videos were also believed to help children's language. The authors stated that play was important to some parents, although, as the illustrative quotes used to support this statement refer to imitation and teaching rather than play, this is less certain. In addition, in the same study, SLTherapists believed that parent perceptions of what constituted play was different to theirs (Marshall et al., 2007).

The language development beliefs of parents of West-African heritage have also been described. Law (2000) conducted in depth interviews with nine parents of children (3-9 years) and three professionals: a SLTherapist, a paediatrician and a nursery teacher and one of whom was of West African heritage. These parents did not consider that a child needed stimulation in order to develop understanding of language i.e. parents' thought hearing their home language is all that would be required. This contrasts with their view that children needed to be taught how to speak properly (Law 2000).

5.1.6 Pre-treatment expectations

Across a number of studies parents elucidated their expectations of SLT including their own role and that of the therapist. In a qualitative study with twenty parents of pre-school children with ASD, parents expected SLTherapists to have specialist knowledge, skills and expertise, to be experienced with children and have an ability to engage them (Auert, Trembath, Arciuli, & Thomas, 2012). This study aimed to explore parent expectations and experiences of evidenced based practice in SLT through four focus groups using a semi-structured topic guide. The authors undertook a thematic analysis using a constant comparative method, involving iterative analyses. Expectations of SLTherapists included providing parents with information, which was also reported in a study by Kummerer and colleagues (2007); and to give parents a practical role in therapy. It was clear in this study that expectations were not always met, for example SLTherapists did not always provide parents with sufficient information about interventions, with the rationale behind treatment decisions often described by parents as

vague or non-existent. This influenced the extent to which parents felt involved and informed and in some cases influenced satisfaction with services.

Lyons, O'Malley, O'Connor, and Monaghan, (2010) also used focus groups but within an action research context, whereby parents views were sought both pre and post intervention. The children (2-3 years) represented by these parents were participating in an eight week early intervention language group. Uncertainty about the role of parents in intervention and the relevance of groups for their child was also expressed. This uncertainty extended to the focus of intervention for some parents such as expecting child-focused treatment rather than strategies to modify parent behaviour. Some studies suggest that parents think the SLTherapists' should work individually with a child, take a lead role and be responsible for goals and intervention planning (Carroll, 2010; Glogowska & Campbell, 2000; Watts Pappas, McAllister, & McLeod, 2016) but to also value parental opinion (Watts Pappas et al., 2016).

Research has also explored parent experience cross culturally, for example in Kummerer and colleagues' study (2007), parents expected that the clinicians should speak the family's language or provide interpreters and expected that treatment should be the same for all families regardless of background. This research explored the views of fourteen Mexican-American mothers representing children (1.5- 3.9 years). The risk of response bias in this study is potentially high as the first author was the primary interventionist for all included children, was fluent in Spanish and also delivered the intervention in the child's primary language (either Spanish or English). This intervention appears to describe the treatment expected by these parents. No limitations were expressed by the authors.

In summary, parents across these studies varied in their views of SLTherapists and their own role in treatment. Expectations were also not always met. Expectations included the SLTherapist taking the lead, delivering individual and effective treatment and providing information to the parent about the nature of the child's problem, the intervention and ways in which to support a child at home.

5.1.7 Intervention Beliefs

Three papers referred to beliefs that parents held about SLT treatment including timing, process and content. In two studies some parents identified that the timing of treatment was important, the sooner the better and desired remediation of the problem before their child began formal schooling (Glogowska & Campbell, 2004; Watts Pappas et al., 2016). Some parents felt there was too much emphasis on assessment and not enough therapy or that they weren't given set activities to do with their child (Glogowska & Campbell 2004) others were unhappy with session timings (Lyons et al., 2010). When children's progress resulted in discharge some parents expressed uncertainty and concern about the future (Lyons et al., 2010).

5.1.8 Relationships in SLT

Relationships with SLTherapists were described by parents in two papers. In a small qualitative study by Pappas and colleagues (2016) with seven children (3.0-5.1 years) parents gave primary importance to the rapport between a SLTherapist and their child. The children in this study had mild to moderate speech sound disorders and received a six week intervention, the details of which were not provided. These parents were interviewed on three occasions: pre, during and post intervention and the data transcripts were analysed using the Framework approach (Ritchie & Lewis, 2003). Effective communication between parent and SLTherapist was also considered essential to working in partnership (Auert et al., 2012; Watts Pappas et al., 2016). Parents felt that respect for parent knowledge and beliefs, the therapists' approachability and ability to support parents were important in establishing an equal relationship with a SLTherapist. Most parents reported positive perspectives on the partnership with the therapist; however, it was acknowledged by some that poor and faltering relationships had negative implications for parents' experiences and child outcome (Auert et al., 2012).

5.1.9 Parent Confidence

Few studies reported comments that were directly related to parent confidence; however, one paper indicated that participants considered their competence as parents to be directly related to their child's SLCN when blaming themselves for their child's difficulties (Glogowska

& Campbell 2004). For children with speech problems, some parents did not have the confidence to remediate their child's speech problems on their own, hence their desire for professional expertise (Pappas et al., 2016). Parental self-efficacy and confidence to help their child may also vary as many parents appear content to help their child first before seeking professional help (Glogowska & Campbell 2004).

5.1.10 Participation

Participation was not explored directly in any of the included studies, although some papers did report parents' views on their role in treatment. Some parents considered their role to be observational and, with support from their SLTherapist, to carry over the intervention to the home (Lyons et al., 2010). A similar expectation was reported by Watts Pappas and colleagues (2016) with parents expecting to carry out homework. In this study home practice was considered to be essential to intervention by some of these parents and others also found it helpful when specific activities were provided.

Barriers to participating were not generally featured; however, one study suggested that an uncooperative child maybe a risk factor to participation during both intervention and when parents were completing home based activities. During these situations parents indicated that they were sometimes required to increase their involvement to support the therapist when their child became uncooperative and to increase their own problem solving skills when this occurred during homework tasks (Watts Pappas et al., 2016). It was not stated how this effected homework completion but poor child engagement and negative perception of therapy influenced parental satisfaction. The authors considered this to be a risk factor for future attendance.

Watts Pappas and colleagues (2016) also commented on parental adherence; in their view a parental belief that a short term problem would require short term treatment was a motivating factor for homework completion. Their justification came from the parents' satisfaction with their level of involvement as compared with studies where parents' of children with pervasive difficulties, with a large amount of daily care and long-term intervention, who were over whelmed with the home practice (e.g. Marshall & Goldbart, 2008). Neither of these papers commented on the theoretical basis that may underpin these views, for example utilising social cognitive models. Complementary explanations using such

models might suggest that, in Watts Pappas and colleagues research (2016), treatment matched parental cognitions and expectations. This may have improved parents understanding of their child's problem, supporting agreement with treatment recommendations and resulting in a coherent model of their child's problem as might be anticipated by the Social Regulation Model (Leventhal et al 2008) and aspects of therapeutic alliance. In Marshall and Goldbart's (2008) study, the multiple demands placed on the family were cumulative and effected their adjustment and ability to cope and, as such, treatment may have become an additional burden as inferred by the Barriers to Treatment Model (Kazdin 1996). Watts Pappas and colleagues (2016) acknowledged that the extent of parent involvement was influenced by multiple factors including beliefs, motivation to help their child, therapeutic relationships and child outcome.

5.1.11 Differences in beliefs

Cross-cultural differences in parents' beliefs about language development have also been explored. In a written survey exploring parent practice and child-directed talk with forty two Chinese Canadian and forty four 'Western' Canadian families, significant differences in beliefs and practice were found between the two groups (Johnston & Wong, 2002). Following multiple regression and discrimination function analyses, Chinese-Canadian mothers were less likely to endorse statements describing the value of play in learning, expanding their child's utterances, the value of encouraging gestures rather than words or those related to joining in adult conversations. They were more likely to agree with statements such as supporting the use of direct instruction and using picture books to develop child language. The opposite held true for Western- Canadian mothers. The survey was developed from western beliefs due to the lack of observational data on Chinese interaction patterns so the results may be an incomplete representation of parenting practices within this group. That said, there are clear differences between the groups that are relevant to service delivery based on 'western' practice.

Similar beliefs have been reported in parents of Indian heritage. Simmons and Johnston (2007) used a written survey with Indian (n=47) and Euro-Canadian (n= 51) mothers to explore practices and beliefs that would influence child-directed talk. Key differences were in the belief that children need to be specifically taught language which was more strongly endorsed by Indian mothers, these mothers also believed that a child's speech errors should be corrected.

The authors believe this reflects an authoritarian style of parenting and being biased towards adult directed methods of language teaching. This style has also been observed in parents of West African heritage living in the UK (Law 2000). Differences were reported between parents' and professionals' perspectives on the role of play and interaction in early education and language development. Professionals felt that parents were unfamiliar with how interaction can promote communication and parents had little awareness of the professionals' view of learning through play and the need to stimulate imagination. The style of Euro-Canadian mothers complemented the typically child-centred and indirect nature of SLT interventions in young children (Simmons & Johnston, 2007) and to the perspectives of professionals (Law 2000). This is in contrast to authoritative approach to parenting observed in Indian and West African mothers.

Marshall et al (2007) examined both the contrasting and complementary beliefs about language development and intervention of SLT therapists and parents. They conducted a qualitative study with fifteen parents of young children referred to SLT and nine SLT therapists experienced in working with young children. Although many beliefs were common to both groups, differences included a parental focus on the need to teach their child, in particular highlighting imitation as important and the value parents gave to TV and videos as a supportive medium for developing language. SLT therapists were equivocal about visual media and not only highlighted play as the main vehicle for intervention but also thought that many parents did not understand the link between language and play, or had different definitions of play. Parents' were aware of the influence of the environment on language but their focus was the provision of social opportunities, whereas SLT therapists were also concerned with the impact of socio-economic factors, having lower expectations of children from certain areas, and mental health within the family, which were not mentioned by parents. SLT therapists also alluded to the competencies of parents such as having inappropriate expectations of a child or not providing the right experiences such as reading stories or leaving the television on. Many therapists were uncomfortable in blaming parents including as a result of socio-economic disadvantage.

In summary, the evidence from this collection of studies suggests that parents of young children with SLCN are attempting to make sense of their child's problem and respond emotionally. Although not explicitly naming symptoms, parents' views on the presence of a problem influences what action they take, for example in facilitating a referral. They are also exploring multiple causes leaving some with uncertainty. This pattern of cognitions is

consistent with Leventhal's SRM (Leventhal et al., 1992). Parents also had clear expectations of SLT some of which were not met and influenced satisfaction. Parents value working in partnership with the SLT and gave importance to the relationship between the child and SLTherapist suggesting that the theme of 'bond' in the therapeutic alliance (TA) is relevant in this context. The differences between parents and SLTherapists views on how children develop language and on SLT interventions may influence agreement with goals and tasks in treatment. Parental beliefs vary both within and across cultures and TA may be particularly pertinent in cultures where an authoritative parenting style is preferred. These studies revealed little about parent confidence, participation and barriers to participating in SLT.

SLT research into attendance and adherence is limited. As described in Chapter 1, some studies indicate that parent beliefs can influence their experience of SLT and their satisfaction but SLT research has not yet explored how parental beliefs might affect participation. Equally many of the theories underpinning treatment participation are under-utilised within this profession, particularly the SRM (Leventhal et al., 1992) which also has implications for measurement. This review provides some indicative evidence that these theories are applicable to SLCN. The current study aims to explore factors that affect parental engagement in SLT intervention by examining potential differences between parents who consistently attended SLT and those who do not. A qualitative design provides an opportunity to explore parent cognitions in relation to SLT, SLCN and participation, and support the adaptation of the Illness Perceptions Questionnaire-Revised (IPQ-R) (Moss Morris et al., 2012) (these data will be reported in chapter 7).

5.2 Aims

- (1) To examine differences between parents who consistently attend SLT and those who do not to explore factors affecting parental engagement in SLT intervention.
- (2) To identify items to be incorporated into the speech and language specific IPQ-R (Moss-Morris et al., 2002) for use with parents of children with SLCN.

5.3 Method

5.3.1 Recruitment

Following confirmation of ethical and Research and Development approval, a data analyst from Lambeth Community Health accessed local electronic patient records to identify potential participants (N=781) whose children were offered SLT in the past 12 months. Initially three groups were envisaged: non-attenders, partial completers and completers. However, given the variability in the number of sessions offered and the low numbers of absolute non-attenders, this was changed to two groups: consistent and inconsistent attenders.

A stepped approach to classifying parents was taken (appendix 5.1). Parents were first classified as consistent attenders if they had over 80% attendance levels and inconsistent if their attendance levels were 50% or less. In the consistent group, a pragmatic decision was made to select seven sessions as the cut off to ensure that consistent attendance was meaningful. To illustrate: a proportion of participants had only been offered one to four appointments so, although their attendance was recorded as between 80-100%, confidence that these individuals could be described as consistent attenders was uncertain. In the inconsistent group there were no restrictions on the number of sessions offered to allow families who were discharged for non-attendance to be included. The local discharge policy indicates that families will be discharged after failure to attend two appointments. Exclusion criteria were then applied.

Parents whose attendance was between 51-79% were then examined for exclusions and number of sessions offered, and subsequently reclassified into either inconsistent or consistent. Those with between 51-65% attendance with a minimum of seven sessions offered, were classified as inconsistent, and those above as consistent (65-79%). This resulted in a final cohort of 216 families to be invited (consistent group=58 , inconsistent=158) (Flow Chart in Appendix 5.1).

Inclusion criteria:

- Parents of young children (< 5 years) with an accepted SLT referral.
- Child offered SLT intervention in past 12 months.

Exclusion criteria:

- A child who had a chronic or current medical illness

- A child who was subject to a child protection enquiry or is a 'Looked After' child.
- A child who had been referred for additional intervention with the lead investigator.
- A parent who required the use of interpreting services.

5.3.2 Procedure

Following the reclassification and application of exclusion criteria potential participants (N=216) were sent a letter of invitation and an information sheet (appendix 5.3). Parents signed and returned a reply slip with their contact details if they were interested in the research, and were subsequently telephoned by the researcher. During this initial call the researcher briefly described the study and then arranged a mutually convenient time and venue to conduct the interview. Written consent was obtained before the interview (appendix 5.4).

5.3.3 The interview

A semi-structured interview was used to examine parental perceptions of (1) the referral process and prescribed intervention, (2) SLT recommendations, (3) the relationship with the SLTherapist; (4) the clinic setting, and (5) reasons for termination of treatment. In addition the interview elicited parental beliefs about their role in language development and illness perceptions related to SLCN (appendix 5.5). Socio-demographic information was also obtained (ethnicity, language spoken at home, family composition, parent employment status and level of education), with any missing data obtained from the child's health records following interview. Information about the child's SLCN, diagnosis and intervention received was also gathered from the child's electronic patient record.

The questions were developed utilising expert consensus by two experienced SLTherapists (the author and Dr Vicky Slonims) and informed by literature. The focus of expert consensus was in ensuring all elements of the process from referral to discharge were captured. Illness perceptions literature was used to ensure that all elements that have previously informed the development of the IPQ-R were covered. Adherence and outcomes literature across medical, psychological and psychiatric domains in adults and paediatrics were used to identify other possible factors that may influence non-participation such as illness perceptions, self-efficacy,

practical barriers, and relationship with the therapist, to allow relevant probes to be included in the interview.

All participants were familiar with their chosen venue. The majority of participants (n=13, 65%) chose to be interviewed at home. For the three participants (15%) who chose to be interviewed at their local clinic, the interview took place in the room where their child received SLT. Three participants (15%) chose to be interviewed in their work place and one (5%) chose to be interviewed at their child's school. Interviews were recorded on a digital Dictaphone with USB transfer and transcribed using a PC. All data were password protected.

The length of the interview averaged 39 minutes (range:17-63); each participant was individually interviewed once. The researcher conducted all interviews. Each interview (in recorded and transcribed form) was given a unique code corresponding to the personal details of that patient, to maintain confidentiality and separation of identifiable personal details from the transcripts. Following the transcription of the audio scripts, the recorded data were destroyed.

5.3.4 Analysis

Sampling in qualitative research typically involves small numbers (e.g. 12-20 cases), with the aim of studying depth and detail and achieving maximum variation (Baum 2002). For the purpose of comparing two groups a sample size of fifteen per group was identified as appropriate.

Framework analysis (Ritchie & Lewis, 2003) was used to develop a thematic framework as a means of classifying and organising the data within the transcribed interviews. This approach is not aligned with any specific epistemological, philosophical, or theoretical approach and as such provides an adaptive flexible tool where the generation of 'themes' is required. Originally part of Grounded Theory, it was developed during the 1980s for applied qualitative research and is now widely used (Gale, Heath, Cameron, Rashid, & Redwood, 2013). This systematic, matrix-based approach allows the researcher to remain close to and grounded in the original transcripts during the process of developing the thematic framework. It facilitates a systematic review of all the data both within and between-cases and easy retrieval of verbatim quotes linked to specific themes or classifications.

This present study required a combined type of analysis; including both inductive and deductive analysis. Although it was not strictly concerned with generating 'theory', this study aimed to identify novel perspectives on participation emerging from the data, but aspects were specifically derived from Leventhal's Social Regulation Theory (SRM). Themes were therefore generated in part, from the data through unrestricted coding (inductive) along with some pre-selected themes (deductive) associated with the SRM to support the development of the illness perceptions questionnaire.

The five stages involved in Framework analysis were followed (familiarisation; identifying a thematic framework; indexing; charting; mapping and interpretation) (Ritchie & Lewis, 2003). The transcripts were read and re-read (familiarisation). On completion of all interviews each transcript was analysed by noting relevant units of meaning and creating free codes (labelling the units of meaning). At the point of free-coding, an independent researcher (Dr C. Graham) completed a coding check on 6 (29%) of the interviews to ensure consistency and reliability in analysis. When the transcripts were compared, they demonstrated that a consistent approach to the data was applied. Some discrepancies were identified; these were related to differences in the language used to describe the observed phenomena for example, 'fear of failure' versus 'parental anxiety about not being good enough'. These were resolved through discussion and agreement was achieved, resulting in some minor changes to the labels used.

The free codes were grouped into coherent themes for each participant and integrated across all to generate a list of super-ordinate themes that captured their shared experiences (identifying the thematic framework). This was initiated by hand and then further refined through the use of Framework Software (Version No. 1.1, O'Connor and Woodfield, 2008). Matrices were produced for each participant, which were headed according to emergent themes with sub-themes highlighted under each titled theme (indexing, charting, and mapping). This resulted in a chart constructed from the themes, with each subtheme represented in a column and each case in a row. Charts were also produced separating the two groups. The final level of analysis involved the examination and interpretation of relationships and interactions between the themes and differences and similarities across the two groups (inconsistent and consistent attenders).

5.4 Results

5.4.1 Response rates

Of the original 216 invitees (58 consistent attenders, 158 inconsistent) 191 did not respond, two letters of invitation were returned marked addressee unknown and two participants returned the letter and declined. Twelve consistent attenders (response rate 21%) and nine inconsistent attenders (response rate 6%) agreed to participate. One respondent in the consistent group was excluded before the study started as interpreting services would have been required, leaving a total of twenty participants representing twenty one children.

5.4.2 Characteristics of sample

The parents/carers

Participants came from a wide range of backgrounds and cultures. Parents identified their own ethnicity (table 5-1); fourteen families (70%) reported the use of one language at home (eight English, six other languages), and six (30%) spoke a combination of English and another language. Mothers formed the majority of interviewees (90%); one father and one aunt (the primary carer for the child) also agreed to be interviewed. Eleven participants (55%) were home makers, four (20%) worked part-time and three (15%) full-time; information was not obtained for two participants. Information was also obtained via self-report about the level of education achieved by mothers; their employment status and also family composition.

Table 5-1 Characteristics of Sample: Parents

Variable		Group Membership:		Total
		Attendance		
		Inconsistent	Consistent	
Employment status	Home maker	3 (15%)	7 (35%)	10 (50%)
	P/T	4 (20%)	0	4 (20%)
	F/T	1 (5%)	3 (15%)	4 (20%)
	not known	1 (5%)	1 (5%)	2 (10%)
Highest education level (maternal)	None	1 (5%)	1 (5%)	2 (10%)
	GSCE Equivalent	4 (20%)	2 (10%)	6 (30%)
	Degree	3 (15%)	8 (40%)	11 (55%)
	Not known	1 (5%)	0	1 (5%)
Ethnicity	Asian Bangladeshi	0	1 (5%)	1 (5%)
	Black African	3 (15%)	1 (5%)	4 (20%)
	Black British African	1 (5%)	0	1 (5%)
	Black British	3 (15%)	1 (5%)	4 (20%)
	Black European	1 (5%)	0	1 (5%)
	White British	0	5 (25%)	5 (25%)
	White Other	1 (5%)	3 (15%)	4 (20%)
Language(s) spoken at home	Bengali	0	1	1
	Danish	1	0	1
	English	4	8	12
	French	2	0	2
	Portuguese	0	1	1
	Russian	1	0	1
	Tigrinya	1	0	1
	Twi	2	0	2
	Yoruba	2	1	3
	One Language only	5(25%)	9(45%)	14(70%)
	English and another			
	another language	4 (20%)	2 (10%)	6 (30%)
	Relationship to child	Mother	9 (45%)	9 (45%)
Father		0	1 (5%)	1 (5%)
Aunt		0	1 (5%)	1 (5%)
2-parent family		3 (15%)	7 (35%)	10 (50%)
1-parent family		6 (30%)	4 (20%)	10 (50%)

The children and SLT Intervention (table 5-2)

The majority (75%) of the participants' children presented with mixed expressive/receptive language difficulties; one had speech difficulties alone, two had expressive language and speech difficulties and one was referred for stammering. Six (30%) also had an additional problem with social communication and eight (40%) presented with additional difficulties in the areas of attention and listening. The children had been offered a range of intervention formats and multiple interventions including therapy delivered in a nursery setting. Nursery intervention is offered as an alternative to the same therapy being delivered in a clinic setting and when less involvement from parents is anticipated. In SLT this decision can be made based on child need but also in situations where parents find it difficult to attend appointments. This intervention was only noted in parents who fell into the inconsistent group. One child had not received any intervention at the point of recruitment, as the parent had not attended any of the sessions offered. One mother was the parent of twins, both of whom had received intervention.

Four children had an additional diagnosis, including Global Developmental Delay, Autism and one diagnosed with a congenital disorder. The primary need of the remaining children was SLCN. There were no differences in the type of SLCN across groups, although slightly more children in the consistent group had additional diagnoses (5 versus 3). The majority (55%) had been involved with a single SLTherapist, with the remainder (35%) receiving input from two to five therapists. Children in the consistent group most commonly worked with a single therapist. All children had received one referral to SLT. Ten children (62%) continued to be active cases, seven (39%) had been discharged and three (14%), although not discharged, had not had any involvement with SLT for at least one year. Following the interview with the researcher two parents, one from each group, sought a re-referral to SLT. In comparison to the inconsistent group, the majority of the children in the consistent group continued to be receiving intervention and, if discharged, this was because treatment was no longer required rather than any other reason.

Table 5-2 Sample Characteristics: Children and SLT Interventions

Variable		Group Membership: Attendance data		
		Inconsistent	Consistent	Total
Mean Age (months)		52.1 (range: 43-62)	50.1 (range: 33-63)	
SLCN Description by SLTherapist	expressive	2	2	4
	receptive	0	0	0
	mixed expressive/receptive	7	8	15
	social communication	3	3	6
	attention and listening	4	4	8
	speech	1	1	2
	stammer	1	0	1
	Feeding	1	0	1
Siblings	0	1 (4.8%)	2 (9.5%)	3 (14.3%)
	1	3 (14.3%)	4 (19%)	7 (33.3%)
	2	3 (14.3%)	3 (14.3%)	6 (28.6%)
	3	2 (14.3%)	2 (9.5%)	4 (23.8%)
Position in Family	Youngest	5 (23.8%)	5 (23.8%)	10 (47.6%)
	Middle	1 (4.8%)	1 (4.8%)	2 (9.6%)
	Eldest	1 (4.8%)	2 (9.5%)	3 (14.3%)
	Twin (youngest)	2 (9.5%)	0	2 (9.5%)
Medical Diagnosis	none	7 (33.3%)	6 (28.6%)	13 (61.9%)
	global developmental delay	1 (4.8%)	2 (9.5%)	3 (14.3%)
	developmental delay	0	2 (9.5%)	2 (9.5%)
	Autism	1 (4.8%)	1 (4.8%)	2 (9.5%)
	Other congenital disorder	1 (4.8%)	0	1 (4.8%)
Type of intervention offered	Advice/home programme	5	3	8
	Language group	7	4	11
	SLI group	0	1	1
	A and L Group	1	3	4
	PCI	0	5	5
	MTW	0	1	1
	Nursery Intervention	3	0	3
	Lidcombe	1	0	1
	Speech Group	0	1	1
	Universal Groups/Services	1	1	2
	offered	15 (range 1-33)	15 (range 7-45)	
	attended	10 (55%)	14 (89%)	
Average time in SLT Service (months)		19.4	16.6	
No. of Speech and Language Therapists involved	1	4 (19%)	7 (33.3%)	11 (52.3%)
	2	1 (4.8%)	3 (14.3%)	4 (19.1%)
	3	1 (4.8%)	1 (4.8%)	2 (9.5%)
	4	3 (14.3%)	0	3 (14.3%)
	5	1 (4.8%)	0	1 (4.8%)
Discharge Reason	Parent Request	2 (9.5%)	0	2 (9.5%)
	Referral inactive 1 year	3 (14.3%)	0	3 (14.3%)
	n/a case active	3 (14.3%)	7 (33.3%)	10 (47.6%)
	non-attendance	1 (4.8%)	0	1 (4.8%)
	Treatment no longer required	1 (4.8%)	4 (19%)	5 (23.8%)

KEY: SLCN: speech, language, communication needs, SLTherapist: speech and language therapist, SLT: speech and language therapy, PCI: Parent Child Interaction 1:1 sessions with parent; MTW: More Than Words Programme Group format with parents; A and L: attention and listening; SLI: Specific Language Impairment; Nursery intervention: includes limited parental involvement; Universal Services: open to all children within a community; Lidcombe: stammering intervention.

5.4.3 Framework Analysis Results: Super-ordinate themes

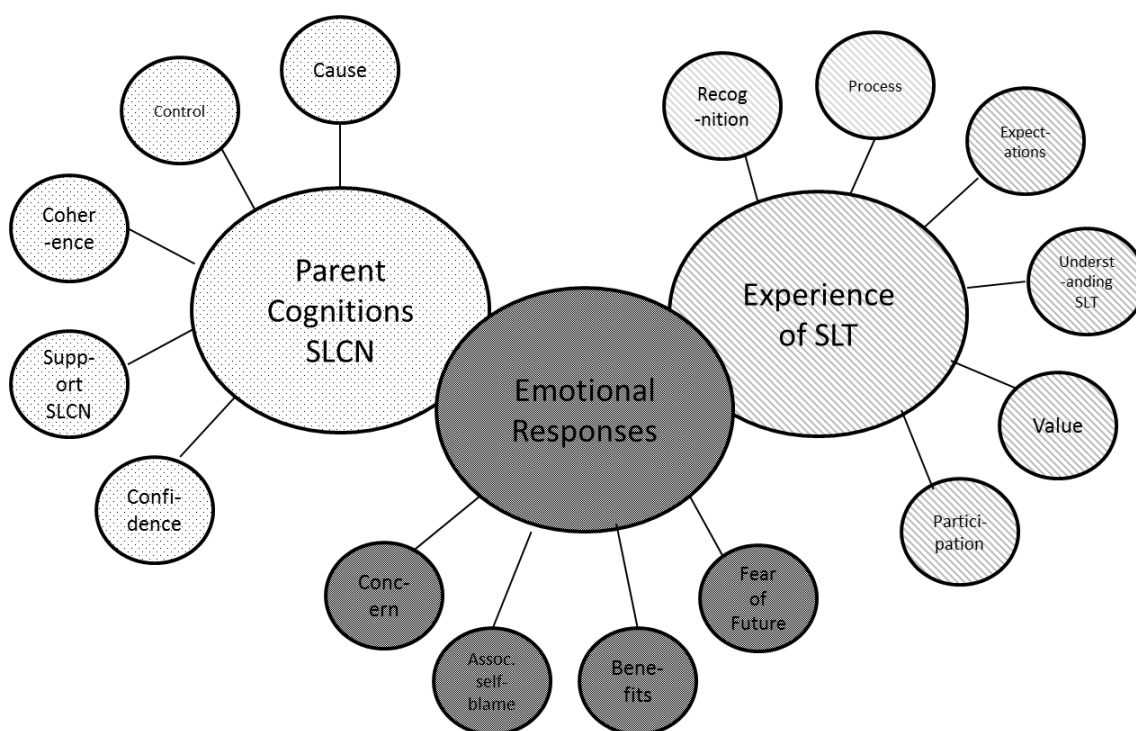


Figure 5-1 Representation of thematic analysis including sub-themes

Three super-ordinate themes captured the views of all parents and are shown in figure 5-1. These themes related to their experience of SLT as well as views, beliefs and emotions that may be important in understanding participation. These were labelled: *Parent Cognitions: SLCN*, *Emotional Responses* and *Experience of Participating in SLT*. *Emotional Responses* was cross-cutting, featuring in all other super-ordinate themes. Within these themes, further sub-themes were identified (figure 5-1, table 5-3). Matrices were subsequently produced to allow a between-case analysis specifically examining any potential differences between consistent and inconsistent attenders that may be important in understanding differences in attendance. Sample matrices are unavailable as following analysis, all data was lost due to an IT incident.

To illustrate the links between subthemes and themes being discussed, the structure represented in Figure 5-1 will be used as a place-marker throughout the results section.

Table 5-3 Thematic Framework

Parent cognitions: SLCN	Emotional Responses	Experience Of SLT
*Causal beliefs	*Concern	*Recognition of the problem
Control over their child's problem	*Negative Emotions and Self-blame	Process
Coherence: understanding SLCN	*Finding Benefits	*Expectations, roles, and relationships in SLT
*Beliefs on supporting communication development	*Fear of the Future	*Understanding of Treatment
*Parental Confidence: helping SLCN		Parent's views on the Value of SLT
		Participation

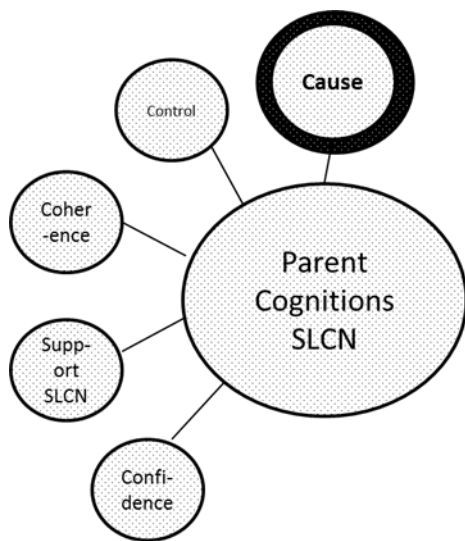
*differences observed between groups

Each theme and subtheme is presented, supported by illustrations from the transcripts. Within each, the views of all parents are reported first, followed by group differences.

5.431 Parent Cognitions: SLCN

Analysis of the transcripts indicated that parents held a range of beliefs linked to their child's communication difficulties. Parents explored the cause and nature of their child's problems as well as how much control they believed they had over their child's SLCN. Also included within this theme were the coherence of parental causal beliefs and their understanding of SLCN. Additional subthemes were parent beliefs about communication development and their confidence in how to support it. For some, their comments suggested links between their beliefs and understanding of their child's problem and the recognition of their child's needs. An undercurrent of anxiety and uncertainty about the nature of their child's difficulties featured throughout these discussions.

Causal Beliefs



A wide range of potential causes were identified by parents, with the majority making multiple attributions. Some parents also acknowledged that they had not thought about what might have caused their child's difficulties until it was raised during the interview.

"Did you ever think, you know, did you ever ask yourself why can she only say one word and not sentences?" (Researcher: PW)

"I'm not ask myself." (610, inconsistent group, language spoken at home: Twi and English, twin's SLCN: mixed)

Hereditary/genetic attributions: The possibility of a genetic or hereditary cause appeared important to many participants. Parents considered which side of the family their child's problems arose from. Some reported maternal origins which also caused additional anxiety for one parent.

"but I just thought, maybe cos my sister had the same, maybe it's from my side that is what I thought and that did make me to get worried." (591, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive)

Some reported that their child's problem came from their husband for example, because he has or had the same problem or there were similar problems in his family.

"I think is improving, but is sometime I think is coming from parent as well you know I think his Dad got little bit, you know, maybe difficulties speaking when he was young [inaudible child in background] .. so I think maybe, maybe it's coming from parent as well sometimes, yeah children, their, they come from parent as well" (600, consistent group, language spoken at home: Bengali, child's SLCN)

For another, the possibility of her son's problem being inherited was considered, but as no-one in her family had these difficulties this mother tentatively concluded that it was unlikely.

"Mm because the reason why I said my children, none of them have it and my family, I don't know who have the same problem as that, I don't know. I've maybe, either sometimes they say maybe from parents or brothers, but my family I don't know, I don't, I haven't seen any of my brothers who have children, I don't know what caused it" (603, inconsistent group, language spoken at home: English and Twi, child's SLCN: mixed, AL, social communication)

Explanations involving certain genes were also reported by two parents. One mother reported that she was informed by a paediatrician that her child's problems were as a result of unspecified subtle genetic defects. Another reported the presence of an identified chromosome imbalance passed from mother to son. Despite these potential concrete explanations for their child's problems a degree of uncertainty about the cause remained.

"Um well there we had genetic testing and there is a chromosomal imbalance that I carry, I carry it in balanced form and [child's name] has it in the unbalanced form .. it doesn't have a name any sort of syndrome that they know of but we've been advised that it's probably contributing to how he presents" (606, consistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

Prematurity was considered to be an important factor by parents in explaining their child's SLCN. This appeared to be from the point of view of the impact on the brain and any effects of medical procedures such as surgery or placement of a naso-gastric feeding tube. Although not stated by these parents, one assumption is that they thought that some physical damage may have resulted from these procedures.

"Yeh she was born as prem like premature baby, early 24 weeks and then she weren't born on oxygen [background noise from child] she had an operation in the night, even doctor was saying that maybe she won't talk because after the surgery you know she lost her voice, she lost her voice for one month, something like that she wasn't cry. I think the doctor really advise me of prevent me, before when she was born, he said that will be one of her disability, the nervosity because I don't know is about the nerve she have a trouble in the brain she had brain

bleed bleeding in the brain". (604, inconsistent group, language spoken at home: French, child SLCN: early feeding, mixed)

The combined vaccination for measles, mumps and rubella (MMR) was also considered, but rejected by two mothers.

"but I don't believe that it was the MMR or anything that tipped him over the edge because with him, his development has always been, it's never been right so" (606, consistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

Other diagnoses: Some parents referred to other diagnoses being responsible for the communication impairment, in particular global developmental delay. For this parent this contributed to greater concern as her awareness of the extent of her son's problems increased (see p.110, 592).

"No, I've got a diagnosis now though, I've only had a diagnosis in the last about 4 months so he's got global delay mental delay, global mental delay, so that'll explain everything then not being talking how he should for his age" (592, consistent group, language spoken at home: English, child SLCN: mixed)

One mother of twins thought her daughter's physical problems arising from hemitrophy and microcephaly affected her communication. This mother appeared to indicate that this was as a result of a lack of space and nutrition in the womb and suggesting that the other twin was responsible for this. Although this mother was observed to laugh, possibly from embarrassment, it was not clear what her emotions were regarding this belief.

"But in my mind I think maybe because of the twins and they are in the one (ha ha) [referring to the womb] I think because of that maybe the other one um what do you call it sleep on the, the [name of Twin 1] sleep in the [name of Twin 2] because of that she and yeh that's what I think about it yeh because of [name of Twin 1] is OK everything is OK on the [name of Twin 1], [name of Twin 1] is fat and then the [name of Twin 2] is a slim so I think [name of Twin 1] take everything (ha ha)" (610, inconsistent group, language spoken at home: Twi and English, twin's SLCN: mixed)

Physiology: From a physiological perspective some parents questioned the involvement of any hearing/listening problems, physical problems, such as a short frenulum limiting tongue movement or behavioural causes such as the use of a dummy.

"He's got a very, I still wonder about this and whether I should go back to the doctor about it, but he's got a very short piece of tissue it's very short and its very close to the end of his tongue whether that affects ch and sh and ss and tss I don't know, so I have question marks whether is a physiological thing and then I also think well is it hereditary? How hereditary are speech patterns I, I just don't know anything about that stuff, so in a way I'm a little but in the dark" (597 consistent group, language spoken at home: English, child's SLCN: speech)

Bilingualism: Parents who spoke more than one language wondered if this was connected to their child's language problems and confused their child.

"I don't know if as well because I'm Portuguese, is like because at home I speak Portuguese and outside when she was in the play or something they would speak English so I don't know if any connection so she was confused Portuguese English that's why it was the delayed" (593, consistent group, language spoken at home: Portuguese, child's SLCN: mixed, AL)

Environmental attributions: Some parents considered the psychological effects of any environmental changes on the child. These included changes in family circumstances such as moving house or moving between houses, or a child having to stay in hospital for a long time. The impact of marital break-up and an unhappy home was also discussed.

"I think also I think the, the other thing was from our point of view, it was whether there was a, I still don't know whether there was a sort of psychological side of things in that [husband's name] and I just didn't really get on with each other and it was all very difficult; when he was young we ended up separating, when he was one and a half I think, two and a half um, so there's always that sort of feeling, you know was he living in an unhappy household and that sort of wasn't encouraging him to thrive? Don't know the answer." (599, consistent group, language spoken at home: English, child's SLCN: speech, expressive)

Two carers for one child were interviewed separately and both raised the psychological impact of the child's mother dying as being part of, but not the sole cause of the child's problems.

"um there's there's been a lot of talk about this um, there's so much speculation it's, it, it, I mean what [name of professor] said was that the death of his mother was a significant thing and it, you know, huge thing in his life so it must have a bearing but it's not the only thing that accounts for this" (594, consistent group, language spoken at home: English, child's SLCN: mixed, AL)

Self-blame: Many parents mentioned the mother's role in relation to cause such as mother's style of talking, not spending enough time with their child, being distracted by changes at home, and one mother referring to the impact of her emotional state and less than optimal

nutrition during pregnancy as possible factors. In all cases where a maternal involvement in cause was mentioned, there was an undercurrent of self-blame. As this was primarily a feature of parents in the CA group it will be discussed further below.

Child factors: Some parents thought that their child's temperament and behavioural characteristics were contributory factors including shyness, lack of confidence and choosing not to talk.

"You know because he's very quiet, even he's not um explain for the teacher even when another children when has hit him or, or swearing because he can't proper talk, thats is it when he is coming home, Mama, he's doing this he's doing this, why you didn't tell the teacher? Because he's not confident to tell maybe he gonna be laugh me that's why. That's why I'm very worried." (605, inconsistent group, language spoken at home: Tigrynian, child's SLCN: mixed, speech, AL)

Some parents thought that their child's SLCN was related to their age, suggesting that as SLCN were common at that age, their child would grow out of it. This may reflect a lack of understanding of typical language development. This appeared relevant to the following parent as she also discussed seeking advice from her family who had expertise in the area of child development.

"that weren't too bad cos they were saying you know he'll pick up more when he starts nursery and you know he's still quite young and so I kind of just thought oh it's not too, you know, yeh I didn't get too worried I was just like OK" (592, consistent group, language spoken at home: English, child SLCN: mixed)

Children's lack of experience in interacting with different people was also discussed and one mother questioned the effects of the demands of starting education so young.

"He [child's father] thought he was he though [child's name] was just like him and that he'd be alright in time but in Ireland [father's name] didn't have to go to school until he was 5 so [child's name] been exposed to that sort of situation since the age of you know 3 and a quarter so you know he's had more pressure in a way, he hasn't been sheltered in the home in the way that [father's name] was" (597 consistent group, language spoken at home: English, child's SLCN: speech)

Differences between groups: *Causal beliefs*

Parents in both groups considered multiple causes of their child's communication difficulties, and also the hereditary nature of SLCN. The main differences were in the attribution of self-blame, the role of a lack of social experience, and the relationship between their child's temperament and behavioural characteristics and their SLCN.

Questioning their own role in causing their child's problems featured most strikingly in the consistent group, with eight parents making reference to blaming themselves in some form.

"but I just think maybe maybe if I'd have started from day, as soon as he was born just talking to him and you know communicating with him maybe, I don't know, maybe that might have helped as well but I just think oh maybe if I weren't so sad and I was a bit happier I might of, it might of he might have just been fine... so I think maybe if I was more healthy yeh healthy pregnant woman that eats loads of food and all the good right foods and maybe that might of affected his IQ as well just kinda better diet" (592, consistent group, language spoken at home: English, child's SLCN: mixed)

Only one parent in the inconsistent group questioned their own role, and this parent subsequently concluded that it wasn't her fault.

"what could be holding him back why is he not speaking clearly cos me and my other son we talk very clearly and fluently at home and talk to him I was always talking so I didn't understand why he wasn't as clear" (609, inconsistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

Parents' views differed on how the lack of social experience contributed to their child's SLCN. Three parents in the inconsistent group reflected on this in comparison to one parent in the consistent group. The focus of experience was different; parents in the inconsistent group focused on a lack of opportunity for peer interaction, whereas the parent in the consistent group referred to interacting with a range of people.

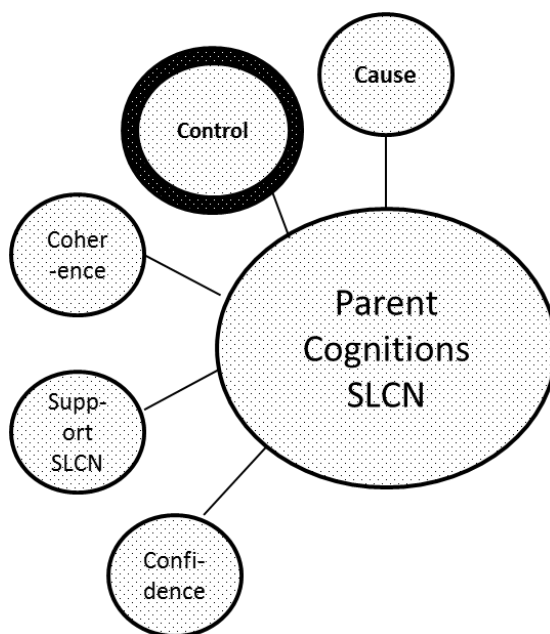
"she [he] started the nursery from [name of nursery] he didn't associate with people because she [he] was the last child of the family so I live in my Daddy's house so with my sisters so [unintelligible] because she's [he's] not so used to baby or used to adult even in [name of nursery] they only said that she's [he's] used to adult so he refused to talk to people she [he] only said, but now when she [he] start school having friend with it can't talk properly" (602, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive, speech, social communication)

The focus of the reported relationship between their child's temperament and behavioural characteristics and cause of SLCN was different across groups. The one parent in the consistent group that mentioned this, viewed it in recognition of her child's strengths. In contrast the two parents in the inconsistent group indicated that their child was in control of their difficulties, for example, accounting for shyness, they could choose to talk if they wanted.

"I think he's more of a creative mind and I think it's his thinking his way of putting the world together in his mind may just not be what most the way most children do it" (596, consistent group, language spoken at home: Danish and English, child SLCN: mixed)

"you can see him the next thing I can just notice from him that maybe he want to be a stammerer some times where he can speak properly because even the he has a teacher in the class [unintelligible] why he start school that time he alway shy to speak to people. She[he] only keep quiet so when they are doing anything she [he] will refuse to talk to anybody because he's a bit shy so that is what I can notice about him." (602, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive, speech, social communication)

Control over their child's problem



When directly asked about control, lack of control over the child's problem was a consistent feature. A number of parents reported that, although they are striving to help and support their children, it is their child who is in control of their difficulties.

"My automatic response is I don't feel like I'm in control of it at all because of his stubbornness, it's very difficult to, to have a cooperation a, a smooth cooperating relationship with [child's name] .. so I feel like his speech issue are like that too, if I show an interest the door gets closed if, um, so I have as much control as I can find a way to er, slip in a repetition of something or boosting his confidence .." (597, consistent group, language spoken at home: English, child's SLCN: speech)

Some parents linked reduced control to factors that they considered were unchangeable including causes of their child's difficulty such as their child's personality or genetic factors.

"but, if that's what it is or not there's nothing I can do to change it [genetic cause] so I'm just more focusing on the therapies.." (606, consistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

At times lack of control was associated with a feeling of being out of depth and not able to help or protect their child or it led to a perception that parents were 'firefighting', only able to manage their child's symptoms rather than understanding, and subsequently addressing, the actual cause.

"But it doesn't, that's not really about control its more about firefighting, we can try and steer him um but we can't force the issue and, and at the end of the day it's down to [child's name] we can help him and try and encourage certain aspects of his behaviour or you know his communication we read, we read with him every night and as we, as we do with his older brother sing and stuff like that but I can't I can't make him do it, if he wants if he wants to make silly noises instead." (596, consistent group, language spoken at home: Danish and English, child SLCN: mixed)

For one carer her personal experience of bereavement seemed to influence her beliefs around control.

"Oo! Ah,(ha ha) don't know I think I've lost my feeling that anyone's in control of their lives at all (long pause) I don't control just seems like the wrong word really I mean I feel like I can support him and I feel like I can try to understand him and I feel like I can help him but I think control's just the wrong word (ha ha) But I would say that about life in general now [following the experience of bereavement]" (595, consistent group, language spoken at home English, child's SLCN: mixed, AL)

Lack of control also appeared to be associated with confidence in their own skills and abilities for example, linking it to the support from the SLTherapist or stating that they are not a specialist.

“Mm Do I have much control? yeh but I haven't got the full control but in my aspect I make sure I do my bit the ones I could do you know I'm not a specialist it's just what I've been asked to do or the little knowledge I've got that's what I'm using. So I wouldn't say 100% total control yeh but at least I'm the first person he got to know with the family” (591, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive)

The impact of the intervention their child was receiving was important with some valuing the positive effects it had on their perception of control.

“In control? um I think I'm in control of his therapy programme because its almost 95% delivered by private er independent therapist who I pay (ha ha) so I feel quite in control in that sense um I think if I didn't have that um I would feel a bit sort of left to do it on my own er yeh I don't know how I'd feel” (606, consistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

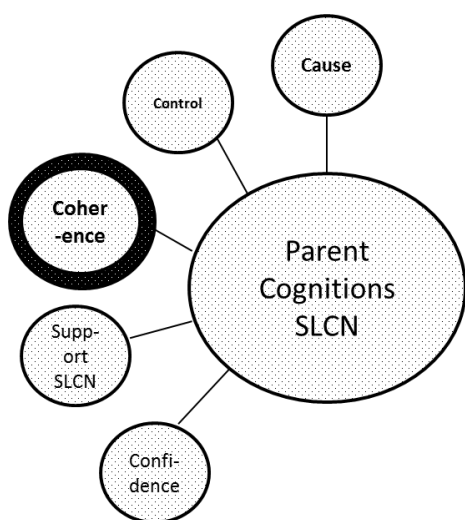
Others however, expressed uncertainty about the degree of control they have because their child's difficulties continued to persist even after intervention and the help they gave.

“Um too hard to control yeh because just they change little a little it's not fast change” (605, inconsistent group, language spoken at home: Tigrynian, child's SLCN: mixed, speech, AL)

Differences between groups: Control

No discernible differences were observed.

Coherence: Understanding SLCN



Throughout the interviews it was clear that many parents did not have a coherent understanding of their child's difficulties. This included confusion around cause, how their child presented and the likely course of their child's SLCN.

Throughout discussions about cause it was apparent that the majority of parents expressed a lack understanding about their child's problem. Many expressed uncertainty when referring to multiple causes and how, if at all, these causes might interact. For example, the role of genetics and the impact of prematurity, and the relationship between physiological explanations and potential behavioural causes such as the mother's role.

"I was I thought to be honest I said oh probably it might be genetic maybe you were born with that .. so I have to like do my own research and see if in the family this sort of issue and I realised my brother in Canada his son is having problem as well with his speech and language even having mild autism .. so that's what I thought but today I don't know the causes. With [child's name] as well because he was born prematurely and um he had to stay in the incubator there for like 2 maybe 3 months with tube inside his throat and also I don't know if all these things contributed so then he couldn't talk quickly so don't know big question mark I don't know." (611, inconsistent group, language spoken at home: French and English, child's SLCN: mixed and AL)

With children who had additional diagnoses, some parents did not appear to understand the medical terminology and implications of these diagnoses. For example, when the term 'delay' had been used by professionals, parents incorrectly believed that their child would catch up or

that if they were behind by a certain number of years then they would always be behind by this amount:

"maybe they will bridge the gap maybe you know cos they said no he'll always, I mean like he's only like a year and a half, he's only like a year and a half sort of from what he should be so even if like through life he's only like a year and a half say when he's 18 say maybe 16 mentally I thought oh that's not too bad" (592, consistent group, language spoken at home: English, child SLCN: mixed)

How a child presented also contributed to a lack of coherence for some. One parent reported not understanding her child's difficulties because sometimes he appears normal, managing tasks that other children might be expected to do.

"I kinda feel that I don't fully still, sometimes I think oh he's normal but you know and then other days I think no he really is perhaps what they say [child turned on TV] see what I mean he looked to the telly and he's managed to turn it on (smile) Oh [child's name]! (Dealt with child) didn't think he could manage the plug in that one it's quite stiff oh! Yeh some days I think (sigh) and then other days I think well he's not too bad" (592, consistent group, language spoken at home: English, child SLCN: mixed)

Personal experience of SLCN resolving spontaneously without intervention, such as in other family members, caused some uncertainty about the likely course of their own child's SLCN.

"I guess the reason at one point I wasn't too worried as well cos we growing up I had a a cousin for years wouldn't talk and at one point I remember hearing as a young child that his parents were worried .. why's he not talking and then I don't know all of a sudden he just talk, started talking and he was fine after that, .. so at one point I thought well you know, he must, in his own time, he will do that, he will, he will talk, his speech will develop, it will just, it will clear, it will be clear eventually" (609, inconsistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

However, the link between personal experience and beliefs about their own child's SLCN was less clear in others.

"yeh and back home there was no nothing like speech therapist you know I'm from Nigeria nothing like speech therapist .. the way she [mother's sister] pronounced but now it's much, much, she talks like normal all that yeh but when she was younger so, that what I was saying to my partner I said maybe that's where [child's name]" (591, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive)

It was common for mothers and fathers to have differing opinions on the nature of their child's SLCN, but this sometimes led to further uncertainty on the mother's part.

"my husband was put forward for the same thing when he was a child as well actually I think he went for an assessment or had an assessment with a child psychologist because his mum was worried that he was too withdrawn but he was she was told like he was normal and healthy child so I don't think he he was too worried about it because I think he just thought she's just following in his footsteps and in turn you know my husband's mum is very kind of quiet and reserved so I think he just thought that's the family way but that's not my family way" (601, consistent group, language spoken at home: English, child's SLCN: expressive, social communication)

Although a lack of coherence was common, for some parents increasing their understanding was part of the process of recognising their child's difficulties, albeit associated with an increased level of concern. Increased understanding was obtained through both experience of assessment and also SLT intervention. For one parent who was initially unconcerned, the subsequent appointments and onwards referrals where she saw a health visitor, then a paediatrician, saw her understanding increase with the final realisation of her son's problems with a SLTherapist.

"I suppose one of these because I had three children all of them are OK I haven't seen these things before so I am always a bit worried but I don't understand I thought maybe it will go by maybe it's different every child is different. That's what I think but when I went to see the health visitor .. But she didn't tell me nothing so all what I get is a letter to [name of clinic] so I went to see another doctor .. I was a bit worried .. the doctor is studying [child's name] but he didn't tell me nothing so when he finished he just tell me this is what's wrong with him this and I, I, I was so upset I was, I was, every time I heard I remember I start crying. I cry a lot.. And I, and then they refer him here to see speech therapist that one here and the woman just say the same thing as when he saw [child's name] she said the same thing .. so here is the first time that I get the right picture because as soon as the lady told me second time, so that was hard to receive; before I said oh ah he's OK" (603, inconsistent group, language spoken at home: English and Twi, child's SLCN: mixed, AL, social communication)

For another parent the process in recognising and accepting her son's needs was difficult as she found someone telling her that her child had problems was offensive. She was however, supported through this with encouragement from friends and family and through participating in SLT.

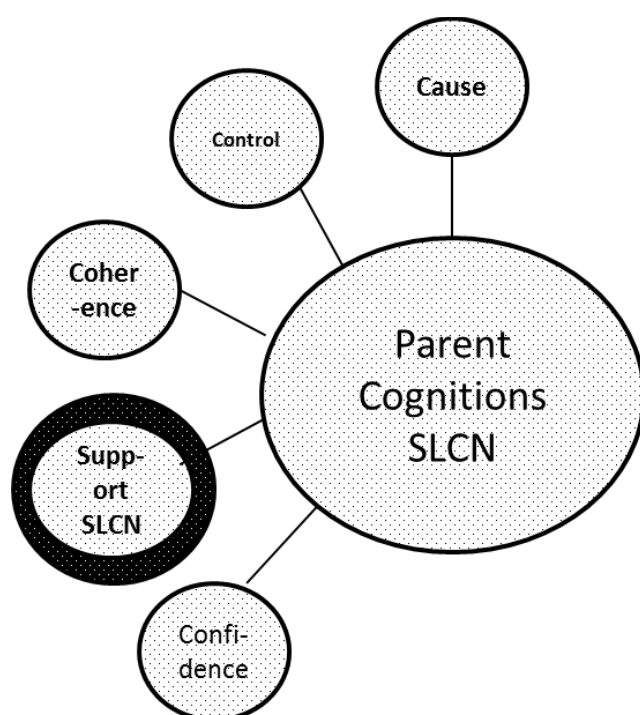
"When, when it was first noted to me I was offended cos I was like I said to you I felt that he just developed in his own time but then when I did go to nursery and I heard another child even

younger than him they were speaking so clearly so fluently so I thought mm maybe he does need a little bit of assistance or help or looking into it what could be holding him back why is he not speaking clearly.. it was I did battle with it for a while as I said it was my friend and my mum that were saying you know give it a try I know you don't want to but if it can help and benefit [child's name] why not give it a try, so OK I brought down my barriers and said OK I didn't and through the experience of [therapist's name] I was OK with it." (609, inconsistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

Differences between groups: *Coherence: understanding SLCN*

No discernible differences were observed.

Supporting communication development: parent beliefs



Parents discussed their beliefs about what facilitates language development. Comments included describing activities and the provision of experiences. Inherent in these descriptions was the significance of parental involvement. Many highlighted the role of social experiences including with themselves, other adults such as grandparents and children, but with different emphasis. Some also described the qualities required of an adult and the relationship with a child that would be beneficial in supporting a child's language development.

“you don’t develop unless you have a relationship with somebody so that’s, you’ve got to have a good attached relationship with someone and then that person’s got to be interested in you want, want to hear what you have to say, they’ve got to talk but they need to listen as well it’s both things um and I think the adult who talks to you needs to be have their ear really open to catch those, those gestures, either of the hand or of a glance a child makes and then what ever might happen with the mouth not to I think some things can get lost or glossed over that are opportunities” (597 consistent group, language spoken at home: English, child’s SLCN: speech)

Interacting with other people was thought to provide experiences or examples of language that the child might imitate. Although the mechanisms between the roles of other people in developing a child’s language might not have always been clear, parents typically recognised that socialising was important.

“Yeh, yeh, I think they will learn just speak with you? And speak with their friends or just look for the book and see the pictures this is the horse this is this, this is you know, just all word in their environment” (593, consistent group, language spoken at home: Portuguese, child’s SLCN: mixed, AL)

For these reasons some parents placed emphasis on the need for children to be with other children such as siblings, cousins and friends and in groups.

“School, school helps them if he start nursery it helps because he meet a lot of children where ever there’s a lot of children they follow them like when [child’s name] started nursery because nursery he started going nor normal children so he copy a lot. He always play with them and things like that but only that he can’t speak but he do everything they do” (603, inconsistent group, language spoken at home: English and Twi, child’s SLCN: mixed, AL, social communication)

Parents also discussed the ways in which they help their own child develop language and, throughout, these discussions it was clear that parents were motivated and put effort into their parenting. Parents considered that talking to their child, providing experiences and giving emotional support, time and attention to their child were important. Talking included telling children to speak, encouraging them by talking about objects and using strategies such as using short clear sentences, language that is slightly more complex than their child’s, being consistent and repetitive, getting their attention before you talk and giving them eye contact.

“The way I consider they develop the language is maybe you give him a book to be reading you ask him what is this what did you read there have you been here or maybe when we going back

on the roadside what is this? Say it. What is that I can say this what is this so I can do that if I develop their language” (602, inconsistent group, language spoken at home: Yoruba, child’s SLCN: expressive, speech, social communication)

Specific strategies included recommendations that parents recalled being made by a SLTherapist but also included some of the parents own ideas. Parents believed that spending time and giving appropriate attention to your child were important, as were a good relationship and creating the right atmosphere in which to learn.

“Oh well they need, they need attention, time, engagement, they model, I mean a lot of it must be modelling, .. I think that’s probably something [SLtherapist’s name] said to me at some stage as well was trying to get his attention when I’m talking to him of get him to look at me and say a word like this [spoke slowly and clearly]” (599, consistent group, language spoken at home: English, child’s SLCN: speech, expressive)

A range of experiences were suggested by parents as being beneficial to the development of communication skills including television, playing music, singing to them, creating novel games, reading, encouraging their children to practice writing and in general taking them to different places to provide a stimulating environment and opportunities for interaction with other children.

“you know television it helps a lot so even this one he started what I noticed that he started learning things from the telly so one day I heard him singing Noddy the song” (603, inconsistent group, language spoken at home: English and Twi, child’s SLCN: mixed, AL, social communication)

Some parents expressed concern that their child’s confidence was related to, and may hinder, their child’s communication, indicating that parents believed that maintaining their child’s self-confidence was important in developing communication skills.

“never ever I think from my perspective tell him something wrong cos what is my advice you’re just killing their self-confidence and the stammering it just really depends on the emotions” (607, inconsistent group, language spoken at home: Russian and English, child’s SLCN: stammer)

For some parents there was a sense that they believed that there was a critical time period in which children can best be helped to develop their language. This was strongly linked to their

own child's difficulties, an under-current of self-blame and, for some, frustration over delays in SLT intervention.

"it's it's just kind of annoying cos it seems like what you get is too little too late and it would have been I think easy to give parents input at a sooner stage um not easy but um you I wish that I'd been able to go on a parent group when I began to have concerns.. Things like that [intervention resources she wanted] shouldn't cost that much compared to what you have to spend when the parents wasted a year because they didn't know what to do. I feel like I did waste quite a bit of time between 18 months and maybe a year a 2 years so I wasted about 6 months." (606, consistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

Many households were bilingual and there was some consistency in parent's beliefs about developing language in this context. All parents who spoke a non-English language at home reported that their child should learn their home language first, giving the same reason that their child would learn English at school or outside the home. Some parents inferred that learning two languages was not easy for their child. This led to some conflict for one parent, as, although she believed her child should learn Yoruba, she also believed she should speak in English because of his SLCN.

"Yeh I've changed the way, because at times I like to speak to him in my language because I know [child's name] has got a speech difficulty and he's learning two languages at the same time so it not easy for him so that's.. um mostly I try to practise my language with him to be [unintelligible] most times I practise in English with him [child's name] why not do this you know most times I practice; I just got to know that I need to him let him understand my language more than English because obviously he's going to understand English and he's going to you know" (591, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive)

For others this was linked to uncertainty about the relationship between being exposed to more than one language and a child's SLCN.

"but just, I just think why is it, what is it that means he can't speak what is it that's going on? Um why? And he, of course you then not only worry about if there's something about the speaking or whether there's something mentally that he's not registering things or that we're doing something wrong that we're not approaching the whole language learning development properly and of course the fact that I speak Danish but I've seen other families do two languages and they and there's nothing to suggest that that's not possible" (596, consistent group, language spoken at home: Danish and English, child SLCN: mixed)

For one mother, although she too had this initial concern, she subsequently changed her mind and appeared confident in her decision to speak her own non-English language at home. This appeared to be related to the SLT intervention received and the positive changes in her child's communication skills.

"And so I always think she was always confused if it's Portuguese or English.. No she's improving her language I can she can speak half Portuguese and half English and now since she I finished the speech group session it's like her speech come out.. No I say different I can see different now because they always tell me it's very important to speak Portuguese at home with all children because when they go to the school they will learn English and that is happen, she speak Portuguese and then outside she speak English" (593, consistent group, language spoken at home: Portuguese, child's SLCN: mixed, AL)

Differences between groups: Supporting communication development

Any differences between groups in this area appeared subtle and related to emphasis. Both groups of parents talked about the importance of key adults such as parents as well as children in developing their child's communication. However, parents in the inconsistent group appeared to place more emphasis on being with other children.

"Well what I believe is when is a group of people or say like it the school now once he has friends you understand?" (602, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive, speech, social communication)

In addition some parents in the inconsistent group needed additional probing during the interview to discuss the role of adults.

"I think it's a lot through what they hear.. I would guess through what they hear around them their environment so it's the um even the programmes they watch on TV yeh just I think their general environment whether it be home nursery whatever social place that they're involved in [probe by PW] Parents siblings grandparents I expect (ha ha) um nursery I guess growing up and then the school" (609, inconsistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

All parents provided suggestions on what they should do across the previously identified areas of talking to their child, providing experiences and giving emotional support, time and attention to their child. Parents in the consistent group often included more detail about the nature of an activity.

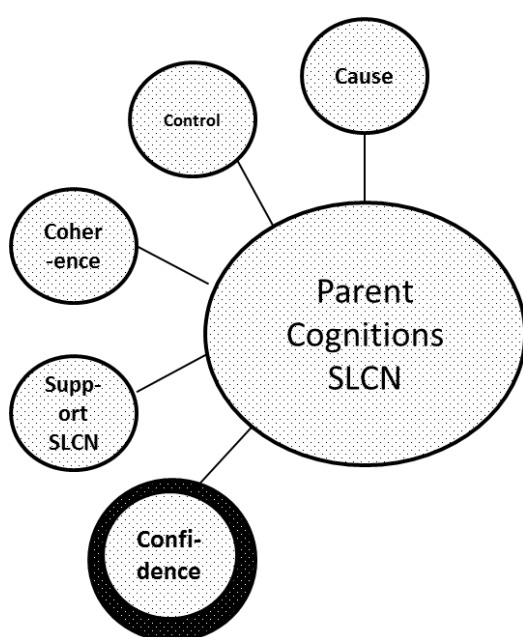
“if they’re using one word sentences you should use two things like that, just slightly more complex language than they’re able to express .. but um er I think just being consistent and being repetitive and songs music, rhythm um just input you know reading stories and um using TV to things that you know that they’re actually watching getting something out of rather than just having it on in the background I feel quite strongly about that. It helps with concentration but um I don’t know um yeh songs you know the kind of songs like the rhyme time that they do in the nurseries round here, .. you take your child and do songs yeh action songs and things like that” (606, consistent group, language spoken at home: English, child’s SLCN: mixed, AL, social communication)

Parents in the inconsistent group focused more on providing opportunities for their child and placing the onus on the child to develop language rather than considering what they might do in an interaction to facilitate communication development.

“they, they look at the parents with the lips movements they learn they, they know what the parent are saying so it’s like that” (604, inconsistent group, language spoken at home: French, child SLCN: mixed)

A number of explanations may be appropriate: the English language competency of parents in the inconsistent group appeared lower than the consistent group which may have limited the accessibility of advice from a SLTherapist. It may also be related to the lower level of participation in this group meaning a reduced level of access to additional knowledge of how children develop language. Parents in this group also appeared to understand the SLT intervention less (see Parents understanding of SLCN and SLT’ section), although all perspectives could be explained by limited explanations of therapy by clinicians.

One final area of potential difference related to the perception of there being a critical time period in which a child can best be supported to develop their communication. This only featured in the consistent group and although only specifically mentioned by two parents, may also be related to the sense of urgency in seeking help within this group and an increased level of concern.



Indications of the degree of confidence felt by parents were revealed through their discussions about SLT recommendations and suggestions they would make to other parents. Two areas emerged as relevant in gauging parent's level of self-efficacy: confidence in following treatment and overall confidence in themselves as parents.

Some parents reported being confident in following SLT recommendations, for some their confidence increased over time. Others suggested that although they lacked the skills of a professional, they were endeavouring to support their child. Homework was generally thought to be easy but actually engaging their child in home practice was harder than expected for some.

"Oh is very difficult to do... Um because for [child's name] sometimes he's listen sometimes not that's why, come [child's name] do that come [child's name] do that because with [the therapist] he knows and then he's very quiet to listen whereas coming home and then when he do er, er, er, (as if child was resisting) (ha ha)." (605, inconsistent group, language spoken at home: Tigrynian, child's SLCN: mixed, speech)

Parents were asked what advice they would give to another parent who also had a child with suspected SLCN. As well as recommending SLT, many parents included practical suggestions on how to help a child develop their language. These ideas were sometimes linked to their beliefs about what was important in helping a child develop language. This may indicate that some

parents had a degree of confidence in their own skills and abilities in helping their child as well as a certain degree of control over their child's treatment and the process of obtaining this help.

[Beliefs] "Um I think it is very important to take out children and meet other children"

[Recommendations to others] "Like to speak to him you know sometime play with him sit down you know follow what he's playing taking him to group other children if can help the child like this" (600, consistent group, language spoken at home: Bengali, child's SLCN)

Similarly when parents talked about their own child many had their own ideas for activities and made their own decisions in relation to whether a strategy or intervention by SLT was appropriate suggesting a degree of self- confidence in their role as parents.

"His talking? I can see that there is many things you can help the children to talk understand as soon as you take something you hide it away then ask him going bring that thing once he find what is this? Say to me. You know sometimes once they watching cartoons in the TV I ask them what they are singing what is this or something like that so I believe you can make him to talk or maybe he was playing with something you snatch it from him and you know he would like to take it back." (602, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive, speech, social communication)

Differences between groups: Confidence: helping SLCN

Differences were observed in parents' confidence in carrying out SLT recommendations and in the area of general parenting self-efficacy. The majority of parents in the consistent group appeared to have confidence in carrying out SLT recommendations.

"very easy, very, very easy but um yes he just yes he kind of got used to them quite quickly" (597, consistent group, language spoken at home: English, child's SLCN: speech)

In contrast a number of parents in the inconsistent group compared themselves negatively with a professional and referring to themselves as not being a specialist. Some in this group also reported that they didn't know how to help their child.

"Um no, no, no for me is a bit difficult I don't know I have support her and I have to try to help her get out, out of [unintelligible]" (604, inconsistent group, language spoken at home: French, child SLCN: mixed)

Parents in the consistent group stated that they would recommend others in their situation to actively seek a referral to SLT. This may indicate that they were empowered by the intervention and perhaps suggesting that felt confident in their own abilities to deliver the intervention at home.

“Oh I would say, try and get in there and get some speech therapy because even if I suspect that a lot of people think that speech therapy is something that you do if you've got a stammer or if you've got a lisp or you can't say your l's or something like that um but actually its I think it's much broader than that and I think it can give them the tools to communicate and, and also the tools to understand things to listen it has all been much broader than I expected and it hasn't just been about can you say 'f' instead of 't' so yes I would I would say that um getting the advice so that you can help your child makes a huge difference” (595, consistent group, language spoken at home: English, child's SLCN: mixed, AL)

Being empowered by the SLT advice received could also be linked to parental beliefs about self-blame and the subsequent recognition of the positive impact changing their behaviour following SLT had on their child. For some though the experience did challenge their confidence in themselves as parents.

“I think as a parent you never ever feel that you do enough ever it, it kind of knocked my confidence a little bit going at the kind of the whole thing because it, it did make me feel like I'd possibly been doing something wrong, although I kind of know really it wasn't it's not about me but it kind of is because when I it seemed that when I modified my behaviour that it, it seemed to make a big difference to how she interacted” (601, consistent group, language spoken at home: English, child's SLCN: expressive, social communication)

Parents' in the consistent group appeared less confident in managing the problem themselves, as evidenced by their sense of urgency in seeking professional help, and that no parent in this group would advise other parents to help their child themselves first. This was associated with having greater concern about their child.

“I would say go to your GP straight away don't, don't muddle around, go and have an assessment and go from there um don't sit back thinking or wondering or imagining it's worse than it is, even, you know, go see someone who can really tell you no you're fine this is all within range but if you want to come and join a little group and do some more talking that's OK too. You know or yes you need to do need to do quite a bit of work you know what ever it might be I would say go along sign up definitely.” (597, consistent group, language spoken at home: English, child's SLCN: speech)

In contrast, there was some evidence that parents in the inconsistent group may have had a greater sense of confidence in their own parenting and decision making. Many of these parents were just as likely to recommend others to help their child themselves first as to seek a referral to SLT. Additionally some of these parents also discussed the cessation of certain strategies when they didn't work.

"I would say depends on what environment the child's in if they're in the nursery just like [child's name] was I I'd probably just suggest maybe looking into before I would even recommend the speech and language therapist it's just to sort of maybe get some books or something to go through with the child and do different you know different er um activities with them appropriate to their age and then if they're still feeling it's not working then ask someone to refer you to a speech and language therapist" (609, inconsistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

A summary of the superordinate theme of Parental Cognitions: SLCN can be found in table 5-4

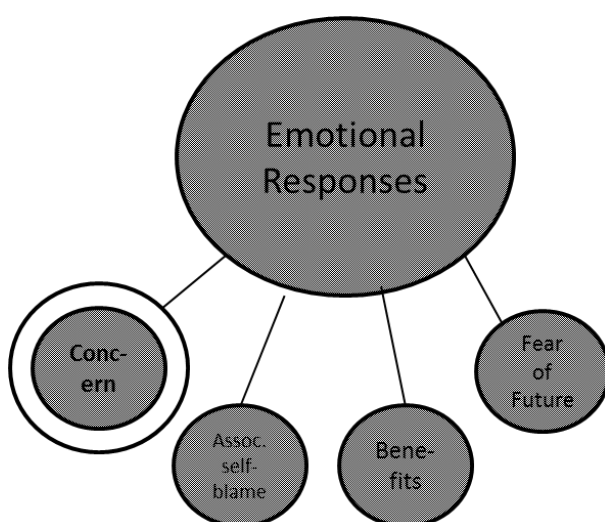
Table 5-4 Summary of Findings: Parent Cognitions SLCN

Theme/ Sub-theme	Consistent Attender group	Inconsistent attender group
Parent Cognitions: SLCN		
Causal attributions	Although parents identified a range of possible causes and considered the possibility of multiple explanations, self-blame was more evident in this group: 'did I do enough?' Uncertainty was also present.	As with the consistent group parents recognised a range of causes and also multiple causes but with uncertainty. A lack of social experience, particularly peer relationships, featured more in this group.
Control	In both groups a lack of control was expressed in relation to causes considered to be unchangeable. Parents noted greater control in relation to child symptoms and treatment, which was also linked to improved outcomes.	
Coherence: SLCN	A lack of understanding about both the cause and for some, the symptoms of their child's problem, was prevalent. Increasing understanding for some was a process gained through experience and repeated engagement with professionals. There were no discernible differences between groups.	
Supporting communication development	Both groups recognised that other people were important both from a socialising perspective and in providing language models for the child. This group placed more emphasis on role of parent and some referred to there being a critical time period in which to intervene.	This group placed more emphasis on being with other children. Their descriptions of how to help their child were broader and lacking detail.
Confidence: helping SLCN	Although these parents questioned their confidence in general parenting they were confident in carrying out home-based recommendations. In helping others in similar situations they	This group appeared confident as parents and were more likely to recommend others to help child first rather than go to SLT. However, some compared themselves negatively to professionals in terms

5.432 Emotional responses

Throughout the interviews, parents revealed a range of emotions both positive and negative. Negative emotions featured most strongly in response to their concerns about their child's SLCN, the impact of parents blaming themselves for certain aspects and their fears for the future. Parents did report some positive emotional aspects, particularly when discussing some of the benefits resulting from their experience of having a child with SLCN, and when positive changes were seen in their child.

Concern



A number of parents expressed anxiety and concern about different aspects of their child's SLCN. For some parents their possible role in causing their child's problem (discussed previously) raised anxiety. One mother gave a cultural explanation for this suggesting that in her culture it is typical for the father to blame the mother for any problems in the child. This cultural explanation may also be pertinent for this parent's worry:

"I just thought maybe cos my sister had the same maybe it's from my side that is what I thought and that did make me to get worried. Well because we had a oh! you know [sigh] people by the way we; have you been to see this you know I wouldn't lie to you the first day the first time I agreed to go and I cried I did cry and I was like and my son have got you know disability in this I didn't see at difficulty I saw it as disability." (591, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive)

As well as anxiety over potentially causing her child's problem, the distress this mother experienced appeared to be a combination of factors. These included being upset as a result of the delays in him being seen and that her efforts to get him seen were not recognised by others as they continued to suggest she sought help. Other factors included her concern about her child having a disability and not being normal, which was also shared by others:

"I was worried because when I look some kids with the same age like her and I said to myself maybe my baby's no normal or something wrong with her." (604, inconsistent group, language spoken at home: French, child's SLCN: early feeding, mixed)

Parents reported concern over the impact of their child's problem both in relation to their child's future development (see Fear of the Future section, p. 117) and the impact on their child's social relationships such as interaction with peers and teachers.

"I think in terms of playtime because he's being told much more that he can't speak properly, that's happening much more at school, so he's more kind of like grumpy about people you know how dare you know they said that about me yeh" (597 consistent group, language spoken at home: English, child's SLCN: speech)

For some parents the level of anxiety increased in recognition of the extent of their child's problem.

"they asked the kids to put something in a box [inaudible] simple box and everybody else did it apart from [child's name] and I just kind of thought oh and my heart sank cos I thought oh dear does he not understand? And that's when I became really worried cos I thought oh gosh if he don't understand then he's got a problem.. er well when he had his last developmental assessment and I said will he like catch up and they said no I was devastated" (592, consistent group, language spoken at home: English, child SLCN: mixed)

In other parents, anxiety reduced following increased understanding of their child's SLCN, in how to help and experiencing positive changes in their child. This may have given them a greater sense of control over their child's problems.

"So when I [child's name] received the same cond [sic] situation autistic I found I was so worried I was so worried you know... but it helps me, my cry, my tears is going down again now I understand because before I don't understand what I [they] mean.. So after that back to speech therapy again and I find speech therapy helps me a lot it helps me a lot because whatever the woman always do it seems like [child's name] well the lady tried to help.. But now his lang his speech is more is not all that it's not clear clearing but is better than before" (603,

inconsistent group, language spoken at home: English and Twi, child's SLCN: mixed, AL, social communication)

Differences between groups: Concern

Parents across both groups expressed anxiety and concern about different aspects of their child's SLCN. In the inconsistent group however, this was often related to concerns about other aspects of their child's development, rather than just about their child's ability to communicate. This may suggest that these parents gave other difficulties greater priority.

"Because first of all my thinking is I was worried about her development which it was too, too slow and she, and she had .. the physical disability and when I look at other kids and I look at her for me I wasn't comfortable yeh I was anxious about her future she will be disabled? Falling back? She won't talk? Or she won't, won't walk? Lot of question in my mind so" (604, inconsistent group, language spoken at home: French, child SLCN: mixed)

Not being concerned, or at least initially, featured more in parents in the inconsistent group.

"when we came I didn't take notice but [child's name] was going around round couldn't speak, all I notice always talking, talking, talking in the in his language and then he do a lot of things here and the woman advised me that that's the reason why they want to help him" (603, inconsistent group, language spoken at home: English and Twi, child's SLCN: mixed, AL, social communication)

One mother did not appear to have recognised her child's SLCN or if she did she did not have any concerns about her child, this resulted in her initially being offended by the suggestion that he might need some help from SLT.

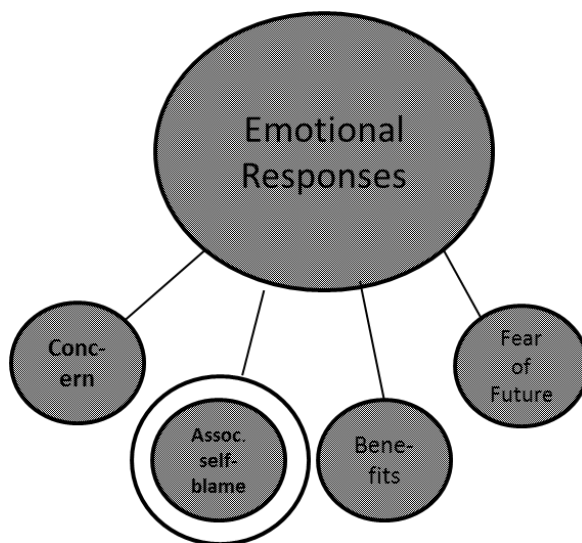
"When, when it was first noted to me I was offended cos I was like I said to you I felt that he just developed in his own time" (609, inconsistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

In contrast, parents in the consistent group appeared to express stronger initial concern about their child's SLCN.

"Um yes because it's not you know I've seen how I know how worried I was about the speech at one point and I was thinking oh he'll never talk he's not really putting together he's not putting he's not making sentences" (596, consistent group, language spoken at home: Danish and English, child SLCN: mixed)

The apparent reduced level of initial concern in the inconsistent attender group may have been related to parents understanding of the development of communication or differences in expectations of communicative milestones in young children. For some in this group it was also related to competing concerns about different aspects of their child's development.

Negative Emotions and Self-blame



A number of parents considered the possibility of their own role having a negative impact on supporting their child's development. Attributing blame to themselves led to parents express a number of negative emotions including guilt, anxiety, sadness and regret. For many this was also linked to lack of control and helplessness.

Parents' reported guilt about not practicing therapy at home, and for one parent this was linked to her perception of not coping with life in general following bereavement.

"even when I was going oh help, can't, I'm not coping, I'm not singing to him enough, I'm not doing this you know all those worries that parents have um and beat themselves up about oh I should do more of this I should do more of that well you know I mean I had that with just a feeling of being very overwhelmed and out of my depth." (595, consistent group, language spoken at home: English, child's SLCN: mixed, AL)

Guilt was also associated with sadness and concern over not being a good parent through not being able to do enough to help their child. Inherent in some statements by parents was that if they had only helped their child more, or differently, their child may not have had SLCN.

"You do you feel a bit hopeless a bit useless. Yeh you do you almost feel like you're failing as a parent Yeh you think yeh what am I doing wrong. I I think I've been I had more time to spend with him than with my other child cos I was working full-time with my other child up until he started primary school then I went to part-time which means he's had me more to himself for you know from, from a very young age from birth." (609, inconsistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

Believing that they had failed to recognise their child's problem soon enough also gave rise to feelings of regret and guilt, with concern about the effect that this might have had on their child's progress.

"I think certainly for me there's always that that worry that there's something that you're not picking up that you should have picked up or if you would intervene earlier it could have been better" (596, consistent group, language spoken at home: Danish and English, child's SLCN: mixed)

Comments referred to the impact of working and personal circumstances on helping their child. One parent appeared resigned to her current situation, but there appeared to be an undercurrent of anger directed towards herself, as well as a degree of helplessness.

" I know it's impossible but it's just I'm very very busy I understand everyone is, but I'm just caught in these circumstances um of course I don't want [child's name] to suffer because of that , but I course if he's getting better and maybe you know its good thing just to wait not to put too much stress on it because I I'm committing myself and I'm not delivering and I hate that" (607, inconsistent group, language spoken at home: Russian and English, child's SLCN: stammer)

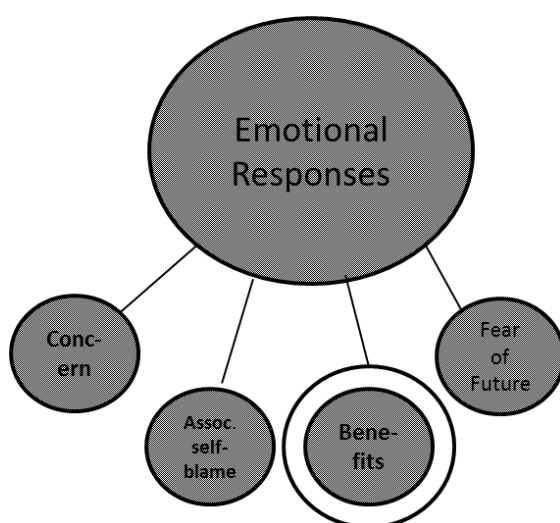
Differences between groups: Negative Emotions and Self-blame

The attribution of self-blame and the associated negative emotions featured strongly in the consistent group, with these parents appearing to constantly question their role and involvement in causing or at least contributing to their child's difficulties. This also appeared to be associated with a reduced level confidence in their skills as parents.

“but I just think maybe, maybe if I'd have started from day as soon as he was born just talking to him and you know communicating with him maybe I don't know maybe that might have helped as well” (592, consistent group, language spoken at home: English, child SLCN: mixed)

This may indicate that parents who believe that they had a role in causing their child's SLCN from an environmental perspective, and which was associated with negative emotions, may be more motivated to change their behaviour to support their child's SLCN.

Finding Benefits



A number of parents were able to find some advantages to having a child with SLCN. Positive benefits related both to the parents themselves and also their children. Parent focused benefits included helping them make a career choice such as working in the National Health Service (NHS) and improving their parenting skills such as being more patient and learning how to communicate with their children, for some this was also reported to be of benefit their other children.

“but now because that helped me as well making [unintelligible] since she was born I saw many many thing concerning the life, which job did I want exactly to make my work why, why what am I am I going to do like nursing doctor or health other people like I received a lot of help from NHS.” (604, inconsistent group, language spoken at home: French, child's SLCN: early feeding, mixed)

One parent also emphasised the changes in her cultural beliefs that were brought about through her experience in having children with SLCN.

"I would tell people which they don't do in Africa in Nigeria which I'm from anybody with a disability they think that person is rotten no disability children they are the most wonderful children ever they are loving and caring." (608, consistent group, language spoken at home: Yoruba and English, child's SLCN: mixed, social communication)

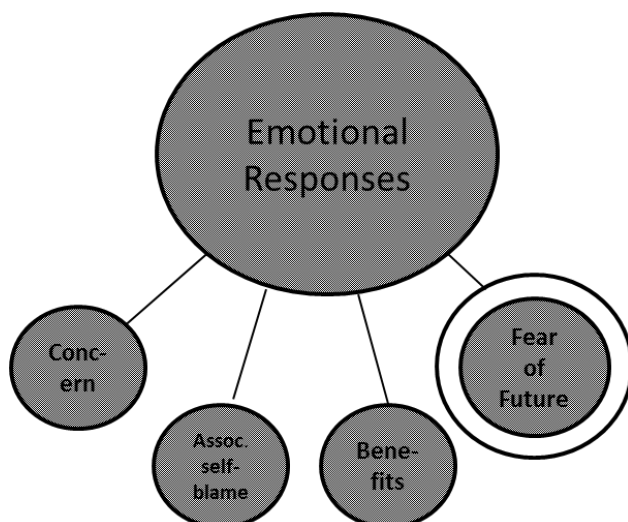
A number of parents also valued their children as individuals and highlighted their strengths as benefits for the future.

"(Ha ha) good things um I think he'll be it'll very interesting to see what things he does I I don't know that he's going to be particularly academic um that's my thinking, he um but I see sparks of, of something bright and unusual as I said before um and although they give me great irritation I like to think it will all come out in that that some of his ecc eccentricities are going to work to his advantage in the end that he isn't completely run of the mill and go onto do great things In other arenas. He's quite he's a bit of a comedian" (596, consistent group, language spoken at home: Danish and English, child's SLCN: mixed)

Differences between groups: Finding Benefits

Finding positive benefits appeared more prevalent in parents who attended SLT consistently, with six parents identifying benefits in this group as compared to two in the inconsistent group. This may indicate that these parents experienced some psychological growth as a result of the challenges of having a child with SLCN. The literature suggests that this type of growth can occur following some form of crisis which results in an individual searching for meaning (Tedeschi & Calhoun, 2004). This could therefore be linked to the differences in levels of initial concern, active help-seeking and the emotional impact of attributing blame onto themselves. Although not explicitly discussed by any parents, these factors may represent the level of severity of their child's SLCN as perceived by a parent. Of note is that four of the six children in the consistent group and one of the two in the inconsistent group have an additional medical diagnosis.

Fear of the Future



Over the course of the interviews many parents communicated some concern and anxiety over what the future holds for their child. This included both the immediate future and moving onwards to secondary school and into adulthood. Emotions such as frustration, anger, anxiety and uncertainty were expressed about delays in being seen, being transferred and after discharge from SLT.

As children started nursery and school, parents were either noticing or anticipating problems their child might have as a result of their SLCN. Parents were concerned about how their child's SLCN might affect their ability to learn and access the school curriculum. Although parents were not explicit, it suggests they might also be anticipating further difficulties in terms of future employment and independence.

"I was beginning to worry about what sort of school he should be going to or whether I'd sort of heard that if you don't if you can't speak fluently by the time you start school then you start getting quite behind because you can't then absorb and interact and develop at school so I was beginning to think about him going to school whether things were going to be OK for that."
(599, consistent group, language spoken at home: English, child's SLCN: speech, expressive)

Some parents also noticed their child's difficulties when interacting with others, leading them to express concern about the future impact of their child's SLCN during social interactions.

"I'm a bit concerned that if he grows with that one will people understand him or if he look like of he have an attitude problem or maybe people will think that he hasn't been brought up properly so I'm just you know getting worried about what he might how it will affect him in the

future I hope that something will be done.” (611, inconsistent group, language spoken at home: French and English, child’s SLCN: mixed and AL)

All parents reported positive improvements and changes as a result of SLT, but many continued to be uncertain, but hopeful about what the future held for their child.

“I think so long as we can keep giving him the level of therapy that we’re doing now we’re giving him the best chance we can but no-one seems to want to tell me where, where, even where he is on the spectrum or the outcome, what’s it gonna be, so kind of hoping for the best but expecting the worst.” (606, consistent group, language spoken at home: English, child’s SLCN: mixed, AL, social communication)

Parents were also keen to reassure other parents who might have a child with similar needs about possible concerns for the future and more specifically about not losing hope. It was in the context of hope that the only reference to an individual’s religion was seen

“I would say just keep on don’t give up hope just even if they tell you he’ll never speak .. I just think that’s probably coming from a religious background .. you will be able to get them to say a word don’t give up.. keep on trying ...” (592, consistent group, language spoken at home: English, child SLCN: mixed)

For some parents, concern about the future was linked to continued difficulties in understanding their child’s problems despite being discharged. This parent was also being mindful of the resource limitations of the SLT service.

“when he was discharged you know you wonder if there was something you need to look out for in the future or I think I asked as much how cos I think [name of SLTherapist] said you know if you’re concerned to come back to us that that the thing that is hardest how to make sure you are concerned um ... it’s almost like you want these little milestones marked out so you can so that you can almost like measure when you should be concerned and when you’re just being overly worried.. Um you do worry a bit but is that because he’s not severe enough to warrant treatment, .. and I can see that that’s fair and there aren’t endless resources for kids speech and language.” (596, consistent group, language spoken at home: Danish and English, child’s SLCN: mixed)

Differences between groups: Fear of the Future

Parents in both groups expressed their concern about their child’s problem; however, the parents in the consistent group appeared to have greater concern about the future for their

child. For many it seemed that they were hopeful that their child's difficulties would resolve by the time they started school but with an underlying fear that they may not.

"because nowadays is everything is so fast the other children if he sees is so fast I want him to pick up really fast as well not to stay behind. If the problem stay like this difficulty for him to speak and understand and because he does not study yet now speaking [inaudible] speaking when the study comes when he goes for primary school and all this and study will come and then he will be learn read and write and all this you know so if that come difficulty so obviously yes I'm worried for that, as a mother I'm worried." (600, consistent group, language spoken at home: Bengali, child's SLCN: mixed)

For this parent, her worry about the future continued despite describing the benefits of SLT and the positive progress they have seen in their child as a result of intervention.

"you know she [SLTherapist] told me a lot of thing to you know bring him out for speaking so I think now he can speak a sentence I want water I want my food so he can make a sentence now before he just speak up one word, he speaking a lot" (600, consistent group, language spoken at home: Bengali, child's SLCN: mixed)

For another parent, concern about the future was related to a lack of perceived change in their child and being somewhat dissatisfied with SLT. This parent also had high expectations of SLT that had not been met (see p. 65, 594).

"people who don't know [child's name] find it very difficult to understand him .. so I'm I'm still concerned that er the older he gets the more than will count against him." (594, consistent group, language spoken at home: English, child's SLCN: mixed, AL)

In contrast, more parents in the inconsistent group appeared confident about the future for their child and this was consistently related to the perceived level of improvement seen in their child.

"he's really changed I'm happy because at times when he say something I just look did he just say that! Yes really impressed, I'm impressed" (591, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive)

A summary of the super-ordinate theme of Emotional Responses can be found in table 5-5.

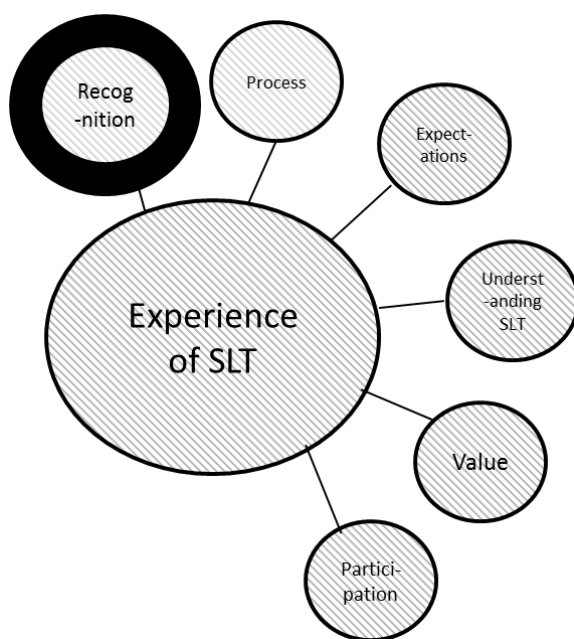
Table 5-5 Summary of Findings: Emotions

Theme/ Sub-theme	Consistent Attender group	Inconsistent attender group
Emotions*		
Concern	Parents appeared to show greater concern, at least initially.	Parents did express worry but this was related to other aspects of child's development rather than communication. It is possible that a lower priority was given to SLCN.
Negative emotions and self-blame	The self-blame expressed by these parents led to expressions of guilt, anxiety, sadness and regret. It was sometimes linked to a perceived lack of control and helplessness and associated with a lack of confidence in their own abilities as parents.	Self-blame did not particularly feature in the inconsistent group.
Fear of the future	Concerns about the future in this group related to the impact of their child's SLCN on social relationships, educational achievement, implying some fear about future employability. Some also continued to express concern even after discharge although many remained hopeful.	Parents in the inconsistent attender group were generally more confident about the future.
Finding benefits	Benefit finding featured more in this group.	

5.433 Experience of SLT

This super-ordinate theme included parent's initial identification of their child's problem, explaining how these difficulties were initially recognised and the subsequent actions they took in seeking help. It incorporated their expectations, views and understanding of SLT, and their experience of different aspects of the process such as from referral to discharge. It captured their satisfaction and which aspects of SLT were valued or not. Parents own views on participating in SLT and any potential barriers were also included.

Recognition of the problem



Parents discussed whether it was themselves or a professional who initially recognised their child's difficulties and how they went about obtaining help for their child, such as using a non-routine or routine medical appointment. Some parents conveyed a sense of urgency about the need to obtain help. Parents' previous experience seemed to be important in recognising their child's difficulties both in terms of whether they had other children but also if they had received SLT before.

"yeh it was me from my experience [with SLT] so I think no she needs help so I went straight away to speak speech therapy because that's why this drop-in is very good for the parents so we can speak directly, directly with speech therapy and she will help to go if we need she [the therapist] will yeh she will say you need [SLT] so we can do the referral" (593, consistent group, language spoken at home: Portuguese, child's SLCN: mixed, AL)

"I noticed like [child's name] I had a three more children somethings like what age a children how talk and what they and talking develop and so I, I feel like he slow talking yeh and, and he just some of the word wrong very much so I talk to the health visitor when I see so for 2 and a half year check and, and tell the health visitor I'm worried about his speaking his slow speaking and she refer me for that speech and language therapy" (600, consistent group, language spoken at home: Bengali, child's SLCN: mixed)

Parent's views of their child's problem could also be changeable, for example, some parents were uncertain at times as to whether there really was a problem with their child's communication:

“Um, I, I was really kind of 50:50 there were days when I’d think Oh you know she’s absolutely fine there isn’t anything wrong you know in inverted commas at all and then there were days when I would doubt myself” (601, consistent group, language spoken at home: English, child’s SLCN: expressive, social communication)

Parent’s level of concern could also change over time, from being initially unconcerned about their child’s SLCN to recognising that their child may need help. For some it seemed to be linked with their perceptions of the anticipated course of their child’s difficulties with expectations that they would resolve spontaneously.

“It was when he had his 2 year check from the health visitor that she noted that he wasn’t speaking and he didn’t seem to have many words for anything .. I knew he was quiet but I didn’t but I wasn’t terribly bothered about it cos he seemed quite happy and healthy thought he’d catch up and then she so she said that she would leave it and come back in I think 6 months” (599, consistent group, language spoken at home: English, child’s SLCN: speech, expressive)

Some parent’s views remained static, and for this parent her lack of concern appeared to be because the problem was specific to certain contexts such as only occurring in school.

“Yeh because of the teacher you know during the time she [he] started school because she [he] refused to talk so that is why the teacher was worried about him so they [unintelligible] but I’m not worried because at home when he’s at home he can talk he talk a lot to us at home” (602, inconsistent group, language spoken at home: Yoruba, child’s SLCN: expressive, speech, social communication)

Parents also discussed the influence others, both adults and children, had in supporting their recognition of the problem and in seeking professional help. Comparing their own children to others of the same age and to siblings was often used as a means of confirming the presence of problems, with one parent going to so far as to check old videos of her older son as a comparator to her younger son. It also heightened anxiety, with some parents being concerned that their child may not be normal.

“Well we were wondering I mean it, it, it just seem, it just seemed that um compared to all his peers nothing much was happening in terms of his speech um, and our oldest boy was late was a late talker as well and people would say oh it’s because you’re speaking two languages and I sort of got that but compared with our oldest, so we checked it out by looking at old videos to see how old he was.. there was a marked difference” (596, consistent group, language spoken at home: Danish and English, child SLCN: mixed)

Friends and family were also important in assisting a parent's recognition of their child's problems and encouraging them to obtain professional help. For some, friends provided general encouragement but parents also benefited from interactions with their friends and families by accessing their knowledge about children and in one case, their specific expertise in child development.

"I actually, I actually was concerned when he was probably about 1 and a half cos my family, my brothers a teacher, it's all kind of that sort of they've got all jobs sort of like that within child development and stuff, like my uncle my gran so, um they were saying that [child's name] should be speaking more better than he is um so that's what brought my awareness to it" (592, consistent group, language spoken at home: English, child SLCN: mixed)

Differences between groups: Recognition of the problem

Parents in both groups sought validation of their child's difficulties through comparing them to other children. Group differences related to whom initially recognised a child's SLCN and the form of help-seeking that followed. Within the inconsistent attender group some parents were notified by professionals of their child's problem rather than initially recognising it themselves. This did not appear to be related to parental experience either in relation to having other children or previous experience of SLT.

"Yeh because of the teacher you know during the time she [he] started school because she [he] refused to talk so that is why the teacher was worried about him" (602, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive, speech, social communication)

In addition, where a parent in the inconsistent group did recognise their child's difficulties themselves, the majority utilised routine appointments rather than perhaps a more active approach of making a non-routine appointment with a medical professional. It is also possible that these parents may not have known where to seek help.

"her sister the other twin she referred to the language speech and language but anytime I going there both of them we going together and then the language speech and language told me the girl that [name of other twin] need help about the talking as well" (610, inconsistent group, language spoken at home: Twi and English, twin's SLCN: mixed)

This is in contrast to parents in the consistent attender group who seemed to be more likely to recognise the problem themselves and use a non-routine appointment to obtain help.

“um well I’m his before his mother died er she was ill I noticed that he was quite cut off um like in the back of the car he would be very much in his own world and his mother wasn’t keen on conventional medicine so um it was only after she died that I was able to take him to the GP myself which I did almost immediately” (594, consistent group, language spoken at home: English, child’s SLCN: mixed, AL)

In addition, three parents in the consistent group actively sought out additional appointments outside of the local NHS. Two parents used their professional contacts; one obtaining an appointment with a professor in child paediatrics, and the second obtaining an appointment at a national centre with a multi-professional team specialising in neuro-developmental disorders.

“not getting anywhere and I didn’t and I just felt in my heart of hearts he hadn’t really the kind of assessment I wanted and I so I sort of spoke to someone who spoke to someone who basically got [name of Professor] name out of [name of hospital] its neurodevelopment yeh and I I didn’t it wasn’t I really thought he was autistic I just wanted someone who had lots of experience to kind of look at my child and do a proper assessment and kind of go is there actually something wrong with this kid or not?” (599, consistent group, language spoken at home: English, child’s SLCN: speech, expressive)

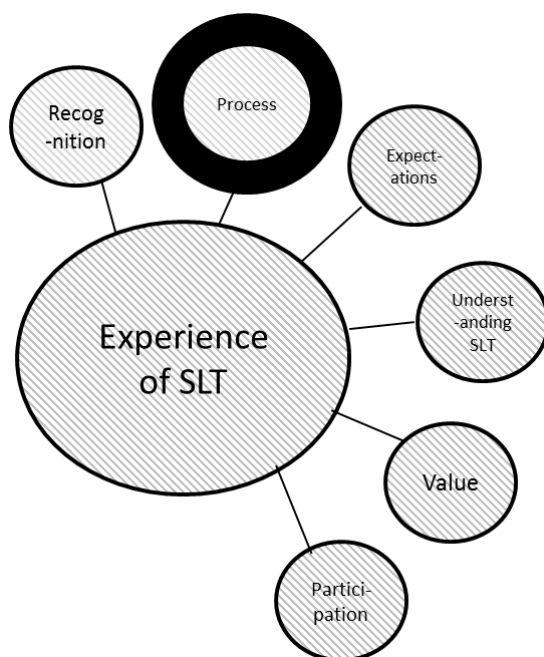
The third parent initially sought help privately including seeing a private paediatrician, purchasing private SLT and hiring a specialist nanny. At the same time as accessing the NHS, she also hired in a team of therapists specialising in a specific intervention for children with autism.

“I’d already actually taken [child’s name] on a few visits to an independent developmental paediatrician because from the age of between 9 months .. we hired um a special needs nanny for 20 hours a week .. I tried to get speech a private speech and language therapist to see him when he was 18 months and she did a very good assessment and established his baseline was very low but um she couldn’t he basically couldn’t be in the room with her ..I’d hired the full team [Applied Behavioural Analysis team] by then end of July and then we went through a phase of trying to sort out the consultant and we finally got the good consultant in the November” (606, consistent group, language spoken at home: English, child’s SLCN: mixed, AL, social communication)

Although not explicitly stated by parents in the consistent group, these observations may be associated with the perceived degree of initial concern about their children and their

continuing concern about the future for their child. It also appeared to be related to a lack of recognised progress in achieving an understanding of their child's difficulties and delays in receiving what they considered to be the right intervention.

Process



'Process' included referral into the SLT service, assessment, intervention and, where appropriate, transfer or discharge. Parents reported a wide range of experiences at the point of referral from being very impressed at the speed to reporting significant delays. Where there were delays, parents' attribution of blame was not always at the SLT service, particularly when the delays were perceived at the point of making the referral rather than after it had been received. Delayed referral to SLT was typically associated with frustration and for some mild anger.

"you know it took them time to get back to us after which he was referred to go for um to see the speech therapist... it got to the stage I said I'm not going to bother myself again because I went to the drop in centre and the lady that was supposed to speech therapist maybe she was off and they were telling me she will get in touch with me for weeks she didn't get back to me you know." (591, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive)

There was also variability in the depth of the description of the child's assessment and very few illustrations suggested the use of formal standardised assessment.

“The assessment she just she asked, first we speak about what was my worries it was just me the speech therapy and [child’s name] and first I speak I tell her what is my worries is because [child’s name] is doing like choo, choo, choo when she want to say something and after the speech therapy set up the room with some toys and she asks [child’s name], for example can I have a cup of tea to see her understanding as well if is the same or can I give me the horse or can you put horsey jumping so it’s like it was like a it was very simple setting for her to understand to see if she’s understanding like simple instructions” (593, consistent group, language spoken at home: Portuguese, child’s SLCN: mixed, AL)

Where the information provided was sparse, it also suggested that some parents may not have fully understood what was being assessed.

“First when she met me and then one to one talk and then and for [child’s name] first she had practices with [child’s name] little and then when she see him and then he must be to put with other groups every Wednesday and then go with [unintelligible] every Wednesday go to 1 o’clock” (605, inconsistent group, language spoken at home: Tigrynian, child’s SLCN: mixed, speech, AL)

Memory may have influenced recall of the details of the therapy and particularly the recommendations.

“Yeh she also gave us homework if I remember correctly, I’m I’m sure it was something to do with the alphabet, alphabet and there was something to do, I had something to do with, I can’t remember exactly but I’m almost certain I can see a alphabet in front of me and a, a square, was it that one? And some fruit, bananas, apples and pineapple, a picture you had to, maybe it wasn’t the alphabet maybe that was something else, maybe he, to, I think he had to put either banana, point out the banana” (609, inconsistent group, language spoken at home: English, child’s SLCN: mixed, AL, social communication)

Transfer from community clinic service into the schools service could also be problematic and cause frustration particularly in relation to the shift in the emphasis of intervention from parent to the educational setting and reported delays in the handover.

“um no the, the only sort of let-down has been where there was a gap in the service like when [child’s name] started [name of nursery] and the person there didn’t see him for the first term and you know he’s only there for three terms so that was I think [Father’s name] and I were both pretty frustrated about that slightly grumpy.. we don’t know what’s going on really at the moment other that I think there is a group activity at the nursery so, I mean yes the personal service we had initially was fantastic [ha ha] um with hindsight a bit of a luxury I think um but

then I suppose that is the difference between being pre-school age and being in nursery as well" (595, consistent group, language spoken at home: English, child's SLCN: mixed, AL)

Where children had been discharged with joint agreement of parents and SLTherapist, this was considered a positive achievement, although many continued to have some level of concern about their child. Some parents continued to show some anxiety and remained under confident about the ongoing management of their child's communication development. For one parent, discharge was a mixture of emotions, including relief over a reduction in the additional demands attending SLT brought to the family. For many, despite involvement in SLT, a lack of understanding about their child's SLCN seemed to persist.

".. that is hardest how to make sure you are concerned... so he was discharged because um I guess because he's of a, a good enough standard in terms of speech ... it's a mixture of things its relief that he is within the range and its almost also probably relief that we don't have to allow for appointments." (596, consistent group, language spoken at home: Danish and English, child SLCN: mixed)

Some parents requested discharge themselves, typically because they did not consider intervention necessary at that point in time. For one parent, this was also associated with the failure of one appointment in particular where the parent appeared to blame to the SLTherapist. However, as the child's health record of this appointment differed, this may have been as a result of a genuine misunderstanding.

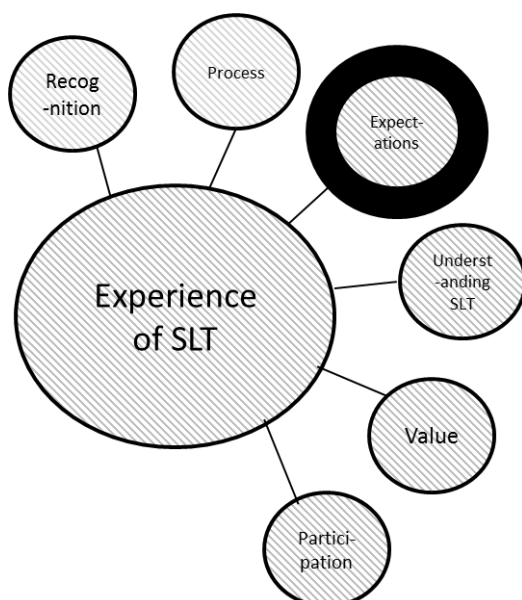
"I said it's not working out I don't want to, to just waste everyone's time it's not efficient if we not follow structure. And it's how we finished actually we are not undergoing this therapy now I just hope we will come back maybe in October when he goes to a school and I will see maybe how it goes with me." (607, inconsistent group, language spoken at home: Russian and English, child's SLCN: stammer)

Others were discharged by the service and where this occurred most parents did not fully understand the reason; two parents did not know they had been discharged (identified from patient records post-interview) and one parent was particularly upset because she had seemingly been discharged because of non-attendance but actually her child had been unwell. Discharge, it seems, was not typically the end of parental concern or anxiety as might have been anticipated and this was sometimes related to a lack of understanding about their child's SLCN and what SLT is able to offer.

Differences between groups: Process

There were no observable differences between groups.

Expectations, roles, and relationships in SLT



Parental expectations included references to the intensity of therapy in that they expected more, and that it would be more scientific including an analysis of their child's difficulties leading to a diagnosis. This suggests that they may have been medicalising the condition expecting the pathway of assessment, diagnosis, treatment and subsequent cure. Parents who commented on this aspect also questioned the level of expertise of therapists and lack of specialism.

"I thought it was gonna be more sort of one to one and the child and really looking into why he's not speaking so in a way I was kinda thinking oh is this it?" (592, consistent group, language spoken at home: English, child SLCN: mixed)

"I think was expecting someone to be able to I don't know sort of like a language scientist almost be able to give me proper diagnosis yes his guttural sounds are like you know or, or I don't know I think in some ways I had this idea of something slightly more scientific I guess an analysis and, and I can see why that might not be possible and it wasn't quite how it, it wasn't what I, I felt I got back, what I got back was more of, sort of saying well he's yeh at this stage we would expect someone to be able to do this, he is within that range but he's delayed." (596, consistent group, language spoken at home: Danish and English, child SLCN: mixed)

Some parents were uncertain about what to expect from SLT but hoped that it would help their child. Therapy aimed at speech and articulation was expected by some even when their child did not have this kind of difficulty, although one parent also commented that she also hoped that it would not be like this.

"I think I probably thought he was gonna be there with a balloon going ba ba ba pa pa pa mu mu mu that sort of thing... No, no it wasn't like that I mean well it wasn't as bad" (599, consistent group, language spoken at home: English, child's SLCN: speech, expressive)

One parent initially thought that SLT did not match the seriousness of her child's needs but this changed with increased understanding of SLT and the subsequent positive changes in her child's SLCN.

"At first it was, I don't know cos this, my son is going through something so serious and she's asking me to do something, you know sort of for the, but it looked like something silly to do something I do normally at home you know someone come with a concern it's like someone goes to the dentist with toothache they say you know what go home and just rinse your mouth you know like things that you were not expecting thinking she was gonna give me some big things to do but actually little thing that were really efficient." (611, inconsistent group, language spoken at home: French and English, child's SLCN: mixed and AL)

SLTherapist role: Inferences about how parents viewed the role of the therapist included carrying out assessments to describe a child's strengths and difficulties and to provide intervention.

"he wasn't really talking much at the moment so at that time so it was quite a lot about her trying to work out what he was responding to and listening to and taking it in and what he might be responding to" (595, consistent group, language spoken at home : English, child's SLCN: mixed, AL)

Some parents believed that the SLTherapist's role in assessment included observing both the parents and the child. Most parents appeared content to be observed and assessed, some found it helpful, although one parents appeared a little surprised initially.

"she was she was very much when she was filming it she sort of said well done to me it was like I was doing well that seemed more important than if Joe was doing well .. it, it, it made me think that what was happening with her was a tiny part of what happens in his life that the emphasis I can understand has to be on the parent cos we're going to do the work" (594, consistent group, language spoken at home: English, child's SLCN: mixed, AL)

The therapist's role in intervention was thought to include educating parents and providing therapy resources for the parent.

"I think just for you to sort of help and encourage the child so you kind of work with the child so although they teaching your child, they're [SLTherapist] also teaching so you can then teach your child at home. That's what I kind of gathered." (609, inconsistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

The SLTherapist's role in making an onward referral to a paediatrician for diagnosis was also mentioned by one parent, with an underlying implication that it is not the role of the SLTherapist to diagnose.

"Yeh she tell me maybe she have er how you say speech disorder that was just, she say, say I'm going to refer her for the doctor for the [name of child development centre] to do development assessment maybe she can have like speech disorder" (593, consistent group, language spoken at home: Portuguese, child's SLCN: mixed, AL)

As well as discussing what therapist's did, parents also talked about what they didn't do such as making a diagnosis and not explaining the cause(s) of their child's problem.

"She, no, well I don't remember exactly but I think her [SLTherapist] emphasis is not on diagnosis er the paediatrician er [name of doctor] had done er test ..he's always he's always been a bit behind um cos I when I first took him to [name of doctor] that was before the speech and language um so not I think the the no assessment was not an emphasis for her that had been done really um she did come her um later on in the work er to do an assessment and that was more following sheets and so on see where he was" (594, consistent group, language spoken at home: English, child's SLCN: mixed, AL)

Parents' role: Parents also considered what their own role might be in supporting the development of their child's communication skills during SLT. At a broad level these included taking their child to appointments and helping their child at home.

"I feel that is like a job I have to do every day or every time to help my baby so I feel I enjoy it" (604, inconsistent group, language spoken at home: French, child SLCN: mixed)

More specifically, they considered their role to include observing the therapist and their child to provide them with the knowledge and skills necessary to carry out the intervention at home.

"I mean obviously a lot of its got to be working with, I think also slightly felt that you realise you're going along you're taking your child but actually you're being taught the speech therapy because you're the person who's gonna do it at home." (599, consistent group, language spoken at home: English, child's SLCN: speech, expressive)

This new role as a therapist for their child sometimes conflicted with other demands of being a parent and had an effect on how much home practice a parent felt able to do with their child. This was often associated with a degree of guilt.

"um I think they worked for us really um there were times when there might have been a homework activity that we didn't manage to do, I mean I'm a single parent so er sometimes er you know [child's sister's name] would have a friend round and I'd be trying to cook supper and da di da and I'd be thinking oh we've got speech therapy tomorrow and I hadn't done that things and we didn't always manage it" (595, consistent group, language spoken at home : English, child's SLCN: mixed, AL)

There was some uncertainty about parental involvement in group interventions with some being unsure of their role in this context, and one other specifically saying she was not expected to be involved with the group intervention. This suggests that parents did not fully understand the process of SLT and expectations of parents within a typical SLT programme.

"Yeh the mum is there, the parent, when we go in all the parents was sitting down there [SLT group] in the, watching them, so when they finish you take your child and go" (610, inconsistent group, language spoken at home: Twi and English, twin's SLCN: mixed)

One parent was active in making resources for her son, but she actually felt that SLT should have this responsibility.

"So we all do the same signs um and PECS you know I don't know how much laminating I've done in the last year but I there should be just just a starter pack for parents it it shouldn't be that you have reinvent the wheel I don't think." (606, consistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

Some parents talked about their job in reminding their children to carry out tasks such as 'doing their homework'.

"So, after we then there I'll just say now it's for you to read your abc so I always tell my daughter, even when I busy cooking for them at home, I tell him give yourself paper and a pencil to be writing something you understand, I, I say anything let him be writing" (602,

inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive, speech, social communication)

Role of others: Parents also considered the roles of others such as paediatricians in making a diagnosis and educational settings monitoring a child's progress in one case and delivering intervention in another.

"is really good cos I spoke to the SEN there the SENCo [special educational needs coordinator] and she's really encouraging and helps me and stuff and we have regular meetings talk about his progress is going and its really good I'm so glad that he got to go into that school" (592, consistent group, language spoken at home: English, child SLCN: mixed)

Siblings were occasionally identified as being important in making the intervention more meaningful in the home setting and also in actually carrying out the therapy or 'homework' rather than the parent.

"and then very often we were set games or activities and we would do them as a sort of threesome with [sister's name] and [she] sort of became [therapists' name] assistant and sometimes if it was half term or something [she] would come along to the appointments as well .." (595, consistent group, language spoken at home: English, child's SLCN: mixed, AL)

Relationships: The relationship between the therapist and both the child and parent seemed to be important in developing and maintaining trust. The majority of parents felt comfortable with the therapist making positive comments both about the relationship and also the personality of the therapist.

"she was really friendly she found me she put me at ease um and she was patient as well and especially when he reacted to the first session not to worry it's perfectly OK." (609, inconsistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

There were some occasions where the relationship faltered, when differences in opinions arose and some occasional references to the competency of the therapist.

"It was comfortable um she's always been very friendly and um try to help but, I, my opinion of her is that she might not be very experienced um and the reason for that is that I've asked her a few questions where she'd had to um consult someone more senior but I didn't think they were that difficult questions." (606, consistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

The majority (95%) of parents provided positive descriptions about the relationship between their child and the therapist including stating that their child liked the therapist, looked forward to seeing her and listened to her. Other comments referred to the therapist qualities in engaging with their child such as having a good way with children, waiting for them to initiate and being warm and confident with children.

"[name of SLTherapist] manner was incredibly quiet low key er and what you know she was perfect for him she was really spot on I was really impressed with her.. he was very shy very withdrawn but she sat on the floor on her knees and just kind of, she persisted just said um you would you like to come and have a look at these? I remember her being very open in her invitation and er she held the invitation she didn't just oh gosh he's not going to do it we'd better pack up and leave now, you know she was very um quietly persistent which gave him the courage." (597, consistent group, language spoken at home: English, child's SLCN: speech)

In the few cases where the child-therapist relationship was not as expected by the parent, this was also related to a perceived lack of intervention and progress. Of note is that the part of the service that the following parent was attending at this time is designed as a universal service for all children and so formal intervention would not usually be offered at this point. This suggests that for whatever reason this parent did not have a full understanding of the SLT offered.

"I actually asked for it not to be [first SLTherapist] because although she was nice, I didn't feel that she'd had any sort of engagement with him she had the opportunity to see him and play with him been going along there for months and nothing really had happened." (599, consistent group, language spoken at home: English, child's SLCN: speech, expressive)

Only one parent in each group reported a negative experience in the relationship between the child and the therapist. The parent in the consistent group subsequently requested a change of therapist. Both parents eventually requested discharge themselves. Of interest is that the parent in the consistent group described herself as non-adherent following the interview as she had never considered SLT to have been of any benefit to her son. This suggests that a poorer child-therapist relationship may have a significant impact on a parent's participation in SLT.

"He saw so many beautiful things in that room and he so basically it kind of shifted, he was telling her what to do, I'm not doing that I'll do it later oh I can do that, so the poor thing she was really struggling.. Yeh brilliant it's OK she's [SLTherapist] really down to earth but it's just I understand she's doing what she's taught to do not taking very proactive er course maybe

every parents thinks that their child is different" (607, inconsistent group, language spoken at home: Russian and English, child's SLCN: stammer)

Differences between groups: Expectations, roles, and relationships in SLT

The expectation that intervention would be more intense was mentioned by some parents in both groups; however, it was only parents in the consistent group who questioned the lack of a scientific approach, diagnosis and expertise. One parent also related his expectations to his own academic background.

"so it seemed er it seemed not much different from going to anyone else who would be nice [smile] so I suppose the, the, the rigorous side of me you know academically trained and expecting some specialism er was thinking well you know there's not much to this but you know the other side of me said well you know well she knows what she's doing" (594, consistent group, language spoken at home: English, child's SLCN: mixed, AL)

In contrast some parents in the inconsistent group did not know what to expect and had fewer opinions.

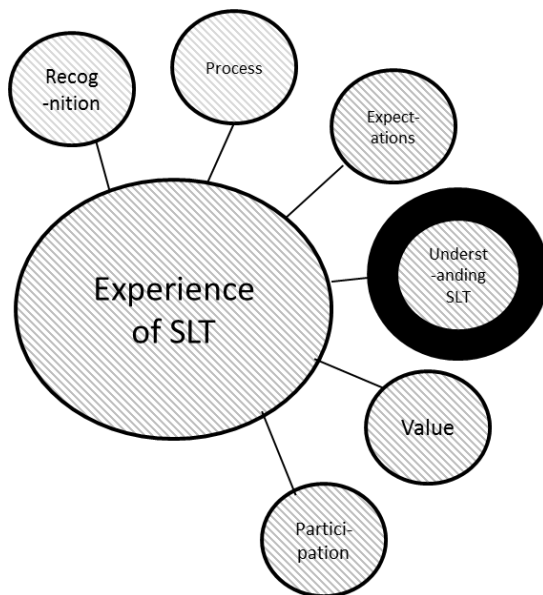
"I don't know what he was she was going to do, I, I don't know cos I know this boy can't speak so I didn't know what she's going to do" (603, inconsistent group, language spoken at home: English and Twi, child's SLCN: mixed, AL, social communication)

Parents in the consistent group may therefore have had higher expectations of SLT than those in the inconsistent group and some of these expectations seem to have not been met. This may also explain why some parents in this group also sought out additional expertise but it is unclear how this might relate to their level of participation.

In the consistent group, differences of opinion with the SLTherapist appeared to be part of a process of the parent developing greater understanding whereas when this arose in the inconsistent group it did appear to cause some difficulties (participant 610, p140).

"one time she the therapist said that er I speak quite slowly so I kinda felt like that were a bit of a knock on me cos I thought well cos I speak slowly is that why he's not speaking so; she never meant nothing by it you know you know when you've got a child like this you kinda every little thing you kinda look for them in yourself or what did I do you know why me or so when she said that I kinda felt oh you know is it cos I speak quite slowly?" (592, consistent group, language spoken at home: English, child SLCN: mixed)

Understanding of Treatment



Across both groups there was some evidence that parents did not fully understand SLT treatment. This included uncertainty as to how SLT could help with one parent who initially dismissed SLT because her child was not yet able to speak at all. This mother believed that SLT would not be helpful until her child was actually talking.

"I never have any idea I never knew about speech language I never knew that. No I, at the beginning for me it was something, nothing, boring, waste of time (ha ha ha). Waste of time at the beginning because I don't know official reason happens at the ends, after that section [SLT session] but now I understand that" (604, inconsistent group, language spoken at home: French, child SLCN: early feeding, mixed)

Therapy approaches and aims were sometimes not understood by parents. Parents questioned why singing might help a child talk; commented that the games suggested did not sound like language and that the group was not a problem rather it was the fact that the child could not talk yet.

"Er oh things like er under you know you do games with him so you're you're hiding things in a bag you're taking them out um bag of being under the sheets and lifting it up, it doesn't sound like language at all (ha ha)" (594, consistent group, language spoken at home: English, child's SLCN: mixed, AL)

One mother had not understood that a particular manual signing system (Makaton) is designed to not just to help a child understand but to enhance verbal communication and the ability to be understood by others, so rejected the possibility of using it with her child. She did however, demonstrate some confidence in her own decisions about treatment for her child.

"Makaton and I said no it doesn't, because to me, although I went for the course, it was for 2 hours or so and I just said I don't think he needs that because he knows, it's not as if he can't talk, he can talk just you need to understand what he's saying" (591, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive)

One parent also found practicing therapy recommendations with her son embarrassing, which may have been related to not fully understanding the aims of particular activities or knowing how to act when her child gave an unexpected response.

"it hasn't been very helpful that one you know like as before I would say to him no you don't say that way you say banana but the therapist told me not to say not to stay that and stop saying oh we don't say that just say oh you -- or say the word as it's supposed to be pronounced if I do that he will look at me funny, that's not what I have said, you know, what are you trying to say? To be honest I did it maybe one two weeks then I couldn't carry on because I felt ridiculous in front of the child so I decide not to do that one so I've carried on with what I used to do, the therapist I know she will be cross, but er maybe I should tell her that it didn't work it wasn't working." (611, inconsistent group, language spoken at home: French and English, child's SLCN: mixed and AL)

The different methods of delivering SLT was also not fully understood by some. One parent was not aware that the part of the service her son was initially in would not be expected to deliver specific SLT intervention rather it was a generic service for all young children (see p.133 participant 599). Lack of coherence was also linked to parents views on their and the SLTherapist's role in helping their child to communicate and their expectations of SLT (see 'Expectations, roles and responsibilities' section, p.128).

Differences between groups: Understanding of Treatment

Differences were observed in parents understanding of both the assessment and actual therapy. Parents in the consistent group seemed more able to identify some of the different aspects of speech, language and communication that were being assessed.

"She brought out some toys and and um asked [child's name] some questions and got him to say whether something a was going in out and she tested his er understanding of language as well um and what else did she do? I can't really remember mm er I think she had a book as well and she went through some pictures and asked him to describe them or similar to what [second SLTherapist] would do where she would when she was evaluating whether he had come on she go through this book with pictures" (596, consistent group, language spoken at home: Danish and English, child SLCN: mixed

Conversely, parents in the inconsistent group focused on the actions of the SLTherapist and were uncertain of the reasoning behind them. A number of parents in this group were also unable to say anything about the assessment at all.

"You know I can't remember I just remember she had a book and a few objects and she was trying to help him identify them or or I guess I'm not sure whether she at one point watched him to see how he reacted to certain books and some things that she had on the room" (609, inconsistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

Not understanding why certain techniques were used was more prevalent in the inconsistent group.

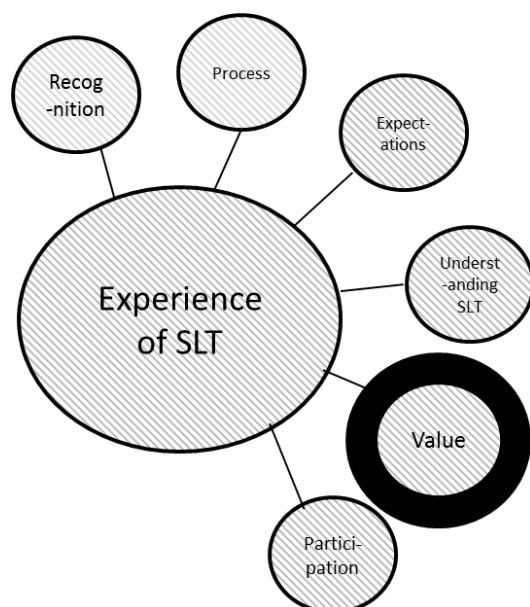
"sometimes when I first started I was thinking why they singing so many of these songs but I guess for their age group I guess it's to help them feel comfortable I guess different words in the songs I thought it would have been more at first I thought there would have been more talking rather than singing but I I know singing it helps to interact doesn't it?" (609, inconsistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

Others in this group did not appear to understand how a group intervention would help a child start to talk.

"Um when we start going for the groups assessments she wasn't like that she was too little .. It was er too boring cos she can't say nothing at that time just sit and look at other um yeh.. The problem is not the group the problem is her because she didn't start talking early so the

problem was her not the group. The group is OK but if she don't talk you can you cannot force her to speak" (604, inconsistent group, language spoken at home: French, child SLCN: mixed)

The Value of SLT



Throughout the interviews parents expressed opinions on what they valued through their experience of receiving SLT for their child. Some parents also revealed aspects of the service or their experience that were less helpful such as occasions where their perceived needs were not being met.

Overall many parents would recommend SLT to others, valued it highly and wanted it to continue. Some did qualify this in terms of quantity (not enough) and quality. Quality included questioning the specialist nature of SLT and also its lack of uniqueness as compared to what parents and an educational setting can also offer. SLT was also sometimes considered to be part of the solution for a child rather than the whole answer. Inherent in some of these responses appeared to be a lack of understanding of the overall aims of SLT including not understanding the complexity involved in what can appear as a simple intervention. Equally the role SLT has in working with and training education staff was either not known or recognised.

"we're happy with his school and everything he's getting there so then I try and not get uptight about it and think is the speech and language so important cos it, it seems so similar to everything else. This is my questions where is the specialism come in? Um if he's getting good

care from us and from the school do we need it?" (594, consistent group, language spoken at home: English, child's SLCN: mixed, AL)

Negative views were less common but these were linked to the outcome for their child and that parents believed they were already carrying out the ideas suggested by the SLTherapist. One parent described therapy as being structured around a traditional family; this did not match her personal circumstances leading to apparent difficulties in participating in SLT. Another parent described how her child would become very distressed when she took him to group therapy, causing embarrassment and further upset in the mother. In some cases the SLT service was not meeting parents' need for information and resources, which left them feeling ill-equipped and under confident in supporting their child.

"what I kept thinking I wish someone would just tell me what is, is going on with him I don't and I think I asked her once to what how, how do I label this how do I sort of you know some children [unintelligible] not speaking as they should do what is it? And I think she described it as a speech deficit with language delay or maybe a language deficit with speech delay or something and that was all I got to me that wasn't enough to understand and have a right approach to it." (599, consistent group, language spoken at home: English, child's SLCN: speech, expressive)

Negative views were linked with the expectations parents had of the role of the SLTherapist. In one case a parent expected the SLTherapist to telephone to find out why her child had not attended as agreed because this did not happen her child was subsequently discharged from the service for failing to attend despite the fact her child had actually been unwell.

"Yeh and I say ah because you are a you [SLTherapist] are a leader of the group if the one child is not coming you know my phone number you know everything (referring to child's additional medical needs) so why you don't call me and ask me this child she never come about 2 he missed two or three lesson why? You don't ask me you don't call me but I come there every day there's no one is there I come every day no one is there and then you send me this letter (discharge letter)" (610, inconsistent group, language spoken at home: Twi and English, twin's SLCN: mixed)

Parents described the impact SLT had both on their child and themselves. SLT was frequently described as being helpful to parents by providing them with tools to help their child, although this was not true for all. The positive benefits included improvements in the area of the child's SLCN and some parents also mentioned other aspects such as improving their child's confidence and commenting on the enjoyment their children obtained from therapy.

"It's fine it was [SLT group] good because the same age and have the same even [child's name] that time was very confident because all of the same problems speech therapy that's why he's more confident" (605, inconsistent group, language spoken at home: Tigrynian, child's SLCN: mixed, speech, AL)

Parents also identified particular facets of intervention that were pertinent to changes in their child, such as the SLTherapist obtaining the child's attention first and groups being particularly helpful in developing certain skills such as taking turns.

"I think what the difference was that the way that she got [child's name] before and, and during the task was the thing that made the difference" (601, consistent group, language spoken at home: English, child's SLCN: expressive, social communication)

Although improvements were seen by many, parents also acknowledged that their child still had skills to develop.

"Well after the input of the speech and language therapist he's getting much much better now he can communicate he knows how to share but he's still a bit bossy." (611, inconsistent group, language spoken at home: French and English, child's SLCN: mixed and AL)

Not all children were described as benefiting from SLT, with one parent suggesting that the approach did not suit her son's personality, another stating that her son was not getting anywhere with SLT, and a third parent described her son as getting variable benefits depending on the type of group intervention he attended. This also seemed to be related to whether the mother herself was able to provide similar activities or experiences or not.

"and then I think shortly after that we were offered a block? Er of 6 sessions and it was a pairs one, it's called listening ladybirds I think and um the most annoying I mean er to be honest the only thing we got out of that block was it's good to take him to a new place where everything's a bit different and he has to get used to it .. but in terms of the actual um activities we did I felt it was a bit of a wasted opportunity .. [child's name] had another .. 6 week block and that was actually, I would say, very useful for us it was er interactive story telling with a few other children and it was obviously parent supported.. but um now you know I've noticed he's a lot better with other children um and the that was a good opportunity because that's not the sort of situation I can make happen at home" (606, consistent group, language spoken at home: English, child's SLCN: mixed, AL, social communication)

In these situations, parents were typically frustrated about wasting time with steps that they considered unnecessary or unsuitable for their child. Parents also did not seem to have been

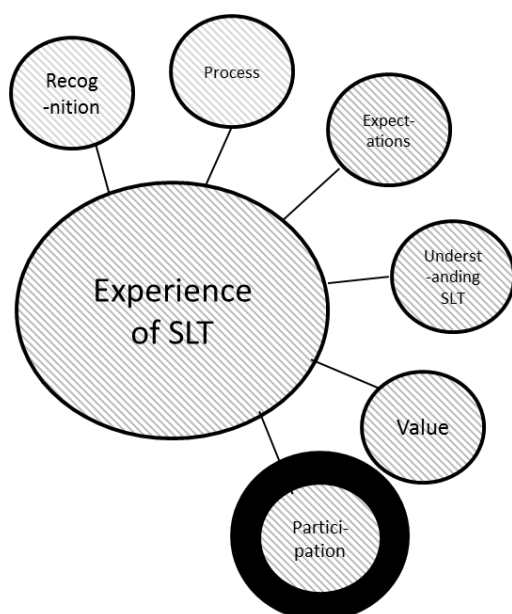
provided with information about why therapy was delivered in this way or, the information provided was insufficient to facilitate their understanding.

"I've thought er that would be more busy but it's kind of um I understand agreed practice how to treat children at this age for this level of stammering I couldn't argue with that but I'm not a professional but I would expect more aggressive approach towards [child's name] and he's really happy with the play but I would expect more erm how to say more person oriented if you see this child is different to another even if he's mild stammer .. so we had to go through this stage of, of basic unnecessarily from my perspective of view. Maybe this is the system is how it works." (607, inconsistent group, language spoken at home: Russian and English, child's SLCN: stammer)

Differences between groups: Value of SLT

No differences were identifiable.

Participation



Level of attendance varied across participants and the interviews provided an opportunity to explore parent's views on attendance and their explanations for non-attendance. In addition, any barriers to following SLT recommendations, as well as attendance, were also explored with parents. These included the location and setting for therapy, work, home and child related factors.

Location: The majority of parents found the setting adequate, child friendly and close to their home. Although for one parent, who worked some distance away, this meant a long commute via the child's nursery to the clinic, and the lack of flexibility with appointment times, made this more challenging.

"it takes about 30 minutes to get from here to home and then take the car get [child's name] from the nursery back to clinic so it's around the whole commute it was about an hour and then if um appointment is er 4 o'clock I'm here [at work] until 7 o'clock sometimes I can't come back to work with [child's name] so it didn't work with me er at all and the, the, the appointments were quite inflexible" (607, inconsistent group, language spoken at home: Russian and English, child's SLCN: stammer)

Initially finding the venue was difficult for one parent. Some parents did report that they had attended more than one setting and that some venues were better than others, for example, two parents described two different venues as "scruffy" and "grim". A common description of the clinic setting was that it was essentially an office with a child friendly corner where the therapy was carried out. Although one parent stated that she would prefer the NHS to spend money on therapists rather than venues, she also appreciated the new health centre she subsequently went to suggesting that location is important.

"there was an office with filing cabinets and cupboards full of toys and you sort of sat around on the floor and it was it was all a bit scruffy but it was fine (ha ha) I you know I don't want them to spend money on a new carpet I'd rather they spent it on therapists but um that was fine and then sort of the last term of group activities were at a new building .. and it was a more spacious room .. so you know it seemed like they had access to a reasonable size room when they needed a bigger room" (595, consistent group, language spoken at home: English, child's SLCN: mixed, AL)

Working: Parents who worked full-time reported more difficulties than those who were in part-time employment or not working, although not all full-time workers raised concerns. Challenges raised included getting time off and the impact of their own fatigue in finding suitable times to practice with their child. Parents who raised these concerns also talked about the guilt they experienced when not being able to meet these demands.

"and the difficult part of it is time. I don't have time because sometimes when I come back from work they [children] want to come and stay with me let me read for them I'm shattered no way just have my shower straight to bed but I feel guilty I'm supposed to be there" (608, consistent

group, language spoken at home: Yoruba and English, child's SLCN: mixed, social communication)

Two parents suggested that not working was an advantage in being able to access therapy and help their child.

"in a way I'm lucky in that I'm not a working mum so the activities that didn't require a, a group as it were things that I could just do 1 on 1 with [child's name] um were easier to fit in" (595, consistent group, language spoken at home: English, child's SLCN: mixed, AL)

Working part-time was described as having an impact only when the hours or days of work clashed with times of therapy groups.

"Um the course the sort of little training he went on the course that he went on was all in the morning and at the time I was working at that time um in the mornings so that made it so which is why [child-minder's name] ended up going I wasn't actually, I said before I was with [child's name] most of the time but actually that period I wasn't um I was working part-time then I wasn't with him for 4 mornings um and there wasn't anything in the afternoons so that that made it a little bit, just made it a bit harder I would have liked to have gone to, to the session myself" (596, consistent group, language spoken at home: Danish and English, child's SLCN: mixed)

Home factors were particularly pertinent in managing to practice therapy homework outside of the clinic setting. The main challenge related to competing demands for time including having more than one child to care for, running a household and the impact of being a single parent or being a part-time parent. This was also associated with a parent's confidence in managing the different roles and responsibilities a parent has. Some parents were more specific in describing barriers, including not having the same therapy materials at home and difficulties in translating therapy into the language spoken at home.

"To participate the harder part is with the other commitments that I have because when you've got three other kids even though its one that needs specific input there are all important because you know kids don't understand that you need to you know get the special time with this person. That was that one was a bit difficult for me you know it hasn't help too much" (611, inconsistent group, language spoken at home: French and English, child's SLCN: mixed and AL)

The child's attention, mood, ability, 'readiness' and interest in activities were considered to be important when practicing therapy at home. Although not always specifically mentioned, this

too seemed to be linked to a parent's perception of their role as a parent versus their 'new' role as a therapist.

"Ah it wasn't that easy for me to carry out at home because of um some of the things she use in doing the session I don't really have it at home on my own so I just had to use the materials I had just to but at times he's not in the mood he's like No mummy I don't want to you know it's not you know when they're outside with their teacher its different from when they're in but I try all I could just to make him I try" (591, inconsistent group, language spoken at home: Yoruba, child's SLCN: expressive)

All parents appeared to consider themselves to be 'good' attenders and played down any absences, only one parent (post interview) identified themselves as being non-adherent. One parent also didn't appear to understand that only telephoning on the day of the appointment to cancel would have an impact on the SLT service.

"Um in fact I supposed to have about 12, I had 6 because that time I was working as well so I had 6 with her I couldn't make it the appointments some of the appointments couldn't make it...Sometimes there was a time when [child's name] wasn't well so I couldn't make the appointment and sometimes either me or had to go to work or something like that...If I couldn't I phone her [SLTherapist] and leave a message always phone her I can't make it today... Yeh I always make sure to let her know before wasting her time" (603, inconsistent group, language spoken at home: English and Twi, child's SLCN: mixed, AL, social communication)

Differences between groups: Participation

Despite the difference in the level of attendance in both groups there were no obvious differences in parent's explanations for non-attendance and their views on any potential barriers to reduced adherence including the clinic setting, work, home and child related factors. All parents considered themselves to be 'good attenders'.

A summary of the super-ordinate theme Experience of SLT can be found in table 5-6.

Table 5-6 Summary of Findings: Experience of Participating in SLT

Theme/ Sub-theme	Consistent Attender group	Inconsistent attender group
Experience of participating in SLT		
Recognition of the problem	The child's problem was more likely to be recognised by parents themselves and they were more likely to seek help via non-routine appointments. Many also sought additional help outside NHS.	In this group, it was professionals who typically noticed first; the one parent who did so used a routine appointment to seek help.
Expectations roles & responsibilities	In this group there were expectations of better quality and quantity, and expectations were not always met. This was potentially related to a greater perception of the severity of their child's problem. In this group differences of opinion with the SLTherapist appeared to lead to greater understanding.	This group were uncertain about what to expect and had fewer opinions. Any differences in opinion with the SLTherapist or service caused some difficulties that were not always resolved.
Understanding of Treatment	Parents were able to recognise the different aspects of SLCN being assessed and how they related to intervention suggesting some understanding of SLT.	The aims and purpose of SLT were not always understood including what was being assessed, particularly intervention techniques and method of service delivery.
Service process	Across both groups parents reported a range of experiences. Some experienced delays in referral, which was associated with frustration and mild anger although not always aimed at the SLT service. When children were transferred to the school SLT service problems could arise. Discharge was considered an achievement even when concern and a lack of understanding about their child's SLCN continued.	
Participation	Despite the differences in level of attendance between the groups there were no obvious differences in this area. All parents considered themselves to be 'good attenders' with only one mother (in the consistent group) identifying herself as non-adherent post interview	
Value	Overall SLT was generally valued by parents and brought positive benefits both to the parent and child; there were few negative views.	

5.5 Discussion

5.5.1 Summary of aims, methods and results.

This qualitative study explored parents' beliefs about their child's communication difficulties and experiences of SLT. Differences between parents who attended consistently and those who did not were highlighted. Twenty parents were interviewed, representing twenty-one young children who had received speech and language therapy (SLT). Eleven parents were classified as attending SLT consistently and nine inconsistently. A thematic framework was developed from the parent interviews using Framework Analysis (Ritchie & Lewis 2003), revealing three super-ordinate themes: parent cognitions: Speech Language Communication Needs (SLCN); emotional responses, which featured throughout all other super-ordinate themes; and experience of SLT (results summaries can be found in tables 5-4 to 5-6).

Parents discussed a number of cognitions about SLCN including causal beliefs, control of their child's problem and the coherence of these and of intervention beliefs. Parents held views on what should be done to support the development of language and communication and how confident they were in their ability to help their child. Many parents responded to their child's SLCN emotionally and with concern, although some also reported benefits. Parents described their experience of SLT including recognition of their child's problem, either by themselves or by a professional, the process of SLT, expectations of SLT and SLTherapists and any associated challenges. The majority of parents valued SLT, including the development of positive relationships, and negative comments were few. Finally, parents considered their participation in SLT, identifying themselves universally as good attenders, but also describing barriers. There were no discernible differences between groups in the multiplicity of causal beliefs, perceptions of control, understanding of SLCN, in their experience of the process of service delivery, and the relationship with the SLT. No differences were seen in the parent reporting of barriers to participating.

The areas common to both groups will be discussed first followed by an exploration of the observed differences between groups and explanations accounting for the differences in attendance.

5.5.2 Perspectives common to the overall cohort.

Parent Cognitions: Collective perspectives on illness coherence, cause, control

A dominant finding to emerge from these interviews was that many parents had difficulty understanding the nature and cause of their child's SLCN and many considered multiple causes, with interactions between them. Not all sought causal explanations, a finding also observed in parents of babies with cleft palate (Nelson, O'Leary, & Weinman, 2009). The range of causes included: genetic, personal (self-blame), medical (child prematurity, vaccination, other diagnoses), physical problems, child characteristics (temperament, age experience) and family circumstances. Comparable causal attributions for SLCN have been reported previously, with parents placing an emphasis on interactions between multiple causes rather than a single cause and which they believed led to greater negative consequences for their child (e.g. Glogowska, 1998; Marshall et al., 2007). Multiple causal attributions have also been observed in parents of children with Autism Spectrum Disorders (ASD) where communication impairments form a core part of the disorder (Huws, Jones, & Ingledew, 2001; Pakenham, Sofronoff, & Samios, 2004). The reporting of multiple causes, along with reporting more symptoms and consequences, is associated with an individual's attempt to make sense of an experience (Hagger & Orbell, 2005; Lobban, Barrowclough, & Jones, 2005; Olsen, Berg, & Wiebe, 2007). The Self-Regulation Model (SRM) labels this meta-cognitive attempt to make sense of a problem as illness coherence (Cameron & Moss-Morris, 2004; Moss-Morris et al., 2002)

In addition to causal beliefs, understanding terminology, perceptions of control and symptom perception all appeared to contribute to the lack of a coherent perspective on their child's SLCN. Parents also did not always fully understand medical terminology or technical jargon associated with SLCN and other diagnoses. This lack of a coherent perspective on their child's problem was linked to parent perceptions of not being in control and for some, increased emotional responses. Inadequate parental understanding has been noted in other qualitative studies within SLT. Parents have been confused about why their child had SLCN, expressed concern about the initial referral, been unsure if a problem actually exists, and whether it is related to a physical or learning problem (Glogowska & Campbell, 2004) or how it is in some children with specific language impairments (SLI), that their child doesn't have a cognitive impairment (Rannard et al., 2004). Difficulties understanding and making sense of problems in children has been observed in parents of children with special needs or Attention Deficit

Hyperactivity Disorder (ADHD) (Bussing, Gary, Mills, & Garvan, 2007; Harborne, Wolpert, & Clare, 2004; Mickelson, Wroble, & Helgeson, 1999). Reduced illness coherence has been associated with a reduction in personal control in relatives of people, including parents, with schizophrenia (Lobban et al., 2005); it is unclear whether parents would respond in similar ways children with SLCN.

In the present study, lack of control featured across both groups and was influenced by factors thought by parents to be unchangeable and with unmet expectations of child outcome and progress. Parental control beliefs about child SLCN and their effects has not been reported in SLT research but it is described in parents of children with other neurodevelopmental problems such as ADHD. In one hundred mothers of children with a confirmed diagnosis of ADHD, problem behaviours in a child and a low perception of control predicted an increase in parental distress (Harrison & Sofronoff, 2002). This research aimed to explore the relative contributions of parental beliefs, knowledge, demographic factors and child characteristics in predicting parent distress. Mothers were required to complete five, psychometrically acceptable questionnaires measuring child behaviour, child attention, parent attribution of cause and control, parent knowledge of ADHD, parent stress and parent depressive symptoms. Demographic information was also obtained. In this study control beliefs (lack of) and child behavioural disturbance predicted increased maternal stress (accounting for child age, sex, medication status and maternal education) accounting for twenty four percent of the variance in maternal stress (Harrison & Sofronoff, 2002). Included children were older (3.8-12.6 years) in this study and with a different diagnosis, limiting its applicability to SLCN. However, behaviour problems are relatively common in young children with SLCN (Lindsay & Dockrell, 2004; Tomblin, Zhang, Buckwalter, & Catts, 2000) so it is feasible that control beliefs may be influential for some parents of children with SLCN, and may influence the experience of negative emotions in some parents. In the present study, parents did not specifically refer to behaviour problems, although many did experience negative emotions.

Child symptoms also contributed to lack of understanding for some parents. This observation is consistent with a study examining the impact of stuttering on children and their parents (Langevin et al., 2010). In this study parents' accounts suggested that the variability in stuttering symptoms in their pre-school child had an impact on parents understanding of their child's problem. The unpredictability of child symptoms also contributed to poorer understanding in a metasynthesis of qualitative studies evaluating maternal experiences of parenting children with a range of disabilities and needs (for example asthma and

schizophrenia) (Nelson, 2002). Although some fields of qualitative research have argued for the inclusion of frequency counts of items under certain conditions (Boyatzis, 1998; Green, 2001), this was not the approach taken here as the purpose of this study was to capture the diversity of views rather than to be representative of a population. Parents did report symptoms, although they were uniformly brief and generic such as “doesn’t talk” or “can’t speak” (appendix 7.1). This brevity may have reflected a lack of understanding of the potential range of symptoms of SLCN and what the different features of communication are. Many aspects of SLCN are not visible and recognition of some aspects of SLCN may be more challenging to parents (Kummerer et al., 2007; Rannard et al., 2004).

From an illness perceptions perspective symptoms alone would not necessarily cause an individual to think that they had a problem or one that required attention. Leventhal’s Self-Regulation Model (SRM) (Leventhal et al., 1992) would indicate that on experiencing symptoms a person will engage in a process of matching these symptoms to ‘disease’ labels that are known to them. Hence it is the label or identity that a person gives to these symptoms that leads them to seek medical care (Cameron & Moss-Morris, 2004). In identifying the problem individuals are attempting to ‘diagnose’. In the present study the only diagnoses reported by parents were medical such as Autism Spectrum Disorder or Developmental Delay. No parent recalled being given a diagnosis such as Specific Language Impairment or Speech Sound Disorder, and when parents recalled SLTherapist’s descriptions of their child’s needs few considered them as an actual diagnosis. The one exception was the mother of a child referred for dysfluency who clearly labelled this as stammering. Similar observations have been reported in parents of older children with SLCN (Roulstone & Lindsay, 2012), suggesting that parents’ difficulties with labelling their child’s SLCN may persist.

Insufficient parent education about the aetiology of SLCN may contribute to difficulties in making sense of their child’s problem. SLCN represents a broad category of needs with no single cause. Furthermore, the cause of sub-categories such as SLI remains elusive and is described as multi-factorial including both internal and external factors (Kovas et al., 2005). It is possible that SLTherapists will advise a parent that cause is currently not known but is due to a combination of factors. In this study, when parents were provided with an opportunity to discuss causality with a SLTherapist, the responses did not enhance parental understanding. In addition SLTherapists may place a different emphasis on causal attributions to those of parents such as social factors in particular, including some parental blame, unless there is evidence to

the contrary (Marshall et al., 2007). There may therefore be some reluctance to be specific about discussing causal attributions directly with parents for this reason.

Parents in this study reported a pattern of beliefs about their child's problem that appears to fit within the categories of illness perceptions proposed by the SRM, with some support from the literature in SLT and other clinical areas. A major challenge for parents was making sense of their child's problem, whether it was in relation to the cause, the terminology, the symptoms (or identity of the problem) or a combination. This was also influenced by a sense of lack of control over their child's problem. These beliefs have the potential to contribute to how a person adjusts to a particular problem and what action an individual takes, that is, how they cope. In the present study parents in the consistent and inconsistent groups responded differently to their child's SLCN as observed in the different patterns of attendance.

Experience of SLT: collective perspectives

In addition to describing the ways in which they tried to make sense of their child's SLCN many parents also talked about their experience of SLT, their relationship with the therapist and perceptions of treatment. Family, friends, comparisons with other children and contact with professionals were influential in recognising a problem in the child pre SLT involvement. This finding is supported by other SLT research (e.g. Rannard et al., 2004) and is also described in the literature on help-seeking (e.g. Godoy, Mian, Eisenhower, & Carter, 2014; Pescosolido, 1992).

Parental experiences of the process of SLT were wide ranging with no obvious differences between the groups. Some parents described being seen quickly following referral with others experiencing excessive delays. Delays were associated with frustration, although not always directed at SLT. Parents described receiving a range of interventions as well as problematic transfers to the school service. Although school aged children are not the focus of this thesis, this may be related to the change in service delivery style across the different arms of the service and the resulting reduction in parent contact. A preference for clinic based services to school aged services in SLT has been previously reported in a qualitative study with seventeen parents of school aged children, and associated with closer collaboration with SLTherapists' and understanding of therapy (Carroll 2010).

Expectations of the SLTherapist included assessment (child and parent), diagnosis, and explanations of their child's problem; which is in keeping with previous SLT research (e.g. Auert et al., 2012; Kummerer et al., 2007). Some parents were disappointed that SLTherapists did not make therapy resources or follow up on non-attendance. The relationship between unmet expectations and parental dissatisfaction has previously been acknowledged in SLT, with Lyons et al (2010) also reporting the influence of a lack of information. In a large (N=154) mixed methods study of parents views of SLT in Australia, a similar association was found with satisfaction, but expectations related to waiting times for therapy, individualised services and engaged professionals (Ruggero et al., 2012). In the current study, when parents agreed with discharge it was viewed positively; self-discharge was usually related to a perception that intervention was not currently needed but, as with other studies (e.g. Lyons et al., 2010), discharge by the service was not well understood. It remains unclear if satisfaction or process difficulties relate to participation, as both groups in the present study described comparable experiences.

Relationships between parents and SLTherapist, and also between therapist and child, were viewed positively by most parents. Poor relationships were associated with a lack of child progress or the parental view of competency of the therapist; one parent asked for a different therapist. Similar observations regarding relationships have been made previously in qualitative studies in SLT (Auert et al., 2012; Watts Pappas et al., 2016) and indicating that, although relationship difficulties may be rare, the personal alliance may be an important factor in understanding participation. Therapeutic alliance has consistently shown a modest relationship with adherence in a review of twenty three studies involving mental health treatment (Thompson & McCabe, 2012).

Parents in both groups valued SLT both in teaching them skills to facilitate their child's development and in achieving positive child outcomes. Many parents would recommend it to others. The small number of negative comments questioned the uniqueness of SLT in comparison to what is offered by educational settings and that it is structured around a traditional family. Some parents reported a mismatch between their perception of their child's needs and what the service offered resulting in what they considered to be unnecessary steps in receiving intervention. Not all parents understood SLT treatment. Different perspectives on SLT treatment between parents and clinicians have been previously reported, with parents, often emphasising imitation and direct teaching other than play (Marshall et al., 2007). Whilst many interventions incorporate these techniques, SLT, including the service within this study,

is often non-directive and child led (Simmons & Johnson 2007). The differences in beliefs may contribute to the few negative perceptions of SLT observed here.

All parents considered themselves good attenders, with parents underplaying non-attendance, particularly in the IA group. It's possible that parents were keen to present themselves in a good light when talking to the researcher despite her efforts to express impartiality. An alternative explanation is that late cancellations are not distinguished from true attendance failures in data management processes. Patients who are discharged from services in these circumstances are likely to experience frustration and dissatisfaction which may affect future attendance (Auert et al., 2012; Powell & Appleton, 2012).

Descriptions of barriers to participation also did not differ between groups. Parents considered the settings and locations adequate, although use of multiple venues meant finding them was an occasional challenge leading to frustration. Working full-time was considered a barrier to participation for some and associated with guilt and fatigue. Managing competing demands, including household tasks and other children, was a particular barrier to carrying out home practice. Translating therapy ideas into their home language was considered a barrier by some as was child compliance with the home-based activities. Time appears to be an underlying factor when the barriers are interpreted as a whole which is not uncommon (Carr et al., 2015; Dreyer et al., 2010). These findings are consistent with other qualitative research in SLT (Watts Pappas et al., 2016), and those reported in a review of qualitative studies of children with long-term conditions (Santer et al., 2014). Participation is thought to be influenced by the number of barriers, representing cumulative burdens, rather than specific types (Kazdin 1996) which may explain the lack of observable differences between groups in this study. The presence of barriers does suggest however, that parents are faced with additional burdens that warrant further investigation when attempting to understand parent participation.

5.5.3 Differences in Parent Perspectives

The differences between groups provide some insight into factors influencing participation. Differences were observed between the two groups in *parental cognitions*: *SLCN* including causal attributions, how to support communication development, and self-efficacy. They also differed in their *emotional responses* and, in the final super-ordinate theme of *experience of SLT*, in their recognition of the problem, their expectations and also understanding of SLT. In

characterising each group these differences are considered in the context of the shared experiences and perspectives of the whole sample.

Overview of the CA group:

In the CA group, self-blame was a dominant feature and was associated with negative emotional responses including guilt, sadness and regret; this group also expressed more negative emotions overall, being particularly concerned at the point of recognition but also about the future. Some parents were able to find some benefits following on from this experience. Although many similarities were observed in the experiences of SLT, parents in the CA group were more likely to have recognised their child's problems themselves, sought out a non-routine health appointment to address it, and to seek additional appointments outside of the NHS. Despite this, some parents experienced sadness and regret over their belief that they had not recognised the problem soon enough. The CA group also emphasised the role of the parent in supporting their child's SLCN, had greater confidence in carrying out SLT recommendations and were likely to recommend SLT to others as a first response to an initial concern. Some parents in this group mentioned there being a critical time period in which children develop language potentially indicating a sense of urgency for intervention.

Overview of IA group:

The views of parents in the IA group differed in many respects. Parents appeared to be more confident about the future and many were less concerned at every stage. They were more likely to be directed to seek help by a professional rather than recognising their child's problem themselves and they placed more emphasis on the role of peers in developing communication skills. They were uncertain of what to expect from SLT, understood the interventions less and were less confident in their ability to carry out recommendations, sometimes comparing themselves negatively with the SLTherapist. Despite valuing SLT they were more likely to recommend that parents' should help themselves and their child rather than advise SLT treatment. This suggested that they may have greater confidence in their parenting skills outside the SLT context. Helping your child first may not be uncommon in SLT even though this may not be acknowledged or recognised by SLTherapists (Marshall et al., 2007).

Parent Cognitions: different perspectives

Self-blame: One of the most notable observations of difference between the two groups was the occurrence of the causal attribution of self-blame in parents in the CA group. The occurrence of this attribution has been reported in parents of children with SLCN previously (Langevin et al., 2010; Rannard et al., 2004). Self-blame is also not exclusive to SLCN as it also occurs in parents of children with intellectual disability (Johnson, O'Reilly, & Vostanis, 2006; Mickelson et al., 1999), ADHD (Harborne et al., 2004; Peters & Jackson, 2009) and cleft palate (Nelson et al., 2009). As with other causal attributions self-blame can arise as a function of an individual's search for meaning and as a pathway to adjust and cope with a significant negative event (Leventhal et al., 2008).

Self-blame also appeared to be related to beliefs that are potentially changeable such as not talking to their child enough or not spending enough time with them. In the literature self-blame is classified into behavioural and characterological categories intending to offer greater insight into the different and sometimes contradictory adaptive responses observed following self-blame (Janoff-Bulman, 1979). In this study the beliefs reported by parents are best classified as behavioural self-blame which is associated with attributions that are modifiable, such as one's own behaviour, controllable and amenable to change (Roesch & Weiner, 2001). In contrast characterological self-blame refers to causes that are unchangeable aspects of an individual such as one's own character. There is therefore potential for individuals who make behavioural self-blame attributions to increase their perception of control over themselves and their environment (Tennen, Affleck, & Gershman, 1986). It is possible that for parents in this study, SLT treatment may have contributed to this change and lead to positive adaptation and active coping through attendance.

The association between self-blame, adaptation and coping has been explored with parents of children who have experienced a traumatic event such as experiencing ill-health. One study (N=100), using a cross-sectional questionnaire design, examined the adjustment of adolescents with cleft palate, and their mothers, to this condition. Questionnaires provided data on parent coping methods, their satisfaction with their child's facial appearance, available social support and parenting stress. The results of a stepwise multiple regression confirmed that self-blame as a coping strategy (accounting for the largest variance, 17.4%), perceived hearing problems, the number of stressful events and venting as a coping strategy were associated with poorer maternal well-being (Berger & Dalton, 2010). Despite this finding, the authors suggested that

in contrast to other treatment types used in the management of cleft palate (for example surgery or dental treatment), participating in SLT may indirectly and positively influence adjustment. SLT may provide parents the opportunity to use problem-solving coping strategies, such as becoming actively involved in homework and therapy. This may in turn influence the extent to which parents feel in control of outcomes for their child (Berger & Dalton, 2010). Similarly in a qualitative study interviewing parents of children with schizophrenia, the authors considered the occurrence of behavioural self-blame to be adaptive (Ferriter & Huband, 2003).

Emotional response: different perspectives

Parents in the CA group reported experiencing many negative emotions about all aspects of their child having SLCN, with anxiety predominating. They worried about delays in getting help and felt guilty about their own role in causing their child's SLCN. Anxiety was also related to a lack of a coherent model of their child's problem and fear for the future. A reduction in anxiety was expressed by some parents as their understanding and knowledge of how to help improved, perhaps giving parents a greater sense of control over their child's problem. For some, anxiety increased once the extent of their child's needs were known, a finding also reported in another qualitative study in SLT (Glogowska & Campbell 2000). Negative mood reactions were also reported by parents of children with a wide range of SLCN (Langevin et al., 2010). Parents in the IA group reported fewer emotions in general. Emotional responses are activated by the perception of symptoms which also play a role in prompting behaviours that may control the symptom(s) (Cameron & Moss-Morris, 2004), as such the degree of emotional response may be the prompt to action for some of these parents and positively influencing participation. Parents are however, known to seek help even when they don't believe that there is a problem with their child (Pavuluri, Luk, & McGee, 1996).

As well as negative emotions, some parents in the CA group also reported finding positive benefits through the experience of having a child with SLCN; this was rare in the IA group. Personal benefits included improving generic parenting skills, enhancing career opportunities, providing social opportunities and for one parent, changing previously held negative views of disability. Parents also valued their child as unique individuals highlighting their strengths. The benefits reported by parents in this study have congruence with those reported by parents of children with Asperger's Syndrome (Pakenham et al., 2004) and with those found in the general benefit finding literature such as greater sense of personal strength, more intimate

relations with others, recognition of new possibilities or paths for one's life (Tedeschi & Calhoun, 2004).

The emotional response of parents in the CA group suggested the experience was emotionally difficult and that at some point these parents experienced their child's SLCN as stressful, perhaps giving a sense of crisis that led to the search for meaning and benefit finding. Benefit finding or stress-related growth occurs in a wide range of people experiencing a variety of significantly stressful events and is a construct used to describe positive ways that people deal with these events (Park & Fenster, 2004). Although in the present study participants' general life experiences were not explored directly, some of those who reported benefit finding did reveal challenging life experiences such as bereavement and the birth of a premature child. Emotional representations have been shown to be positively correlated with benefit finding (Michel, Taylor, Absolom, & Eiser, 2010). It is thought that stressful events significantly challenge a person's way of understanding their world and cause a person to reappraise their life (Bellizzi & Blank, 2006; Tomich & Helgeson, 2004). Engaging in the appraisal and feedback process in personal life reappraisals following traumatic health experiences, also has parallels with Leventhal's SRM (Leventhal et al., 1992).

Theoretical Perspectives

Severity: Parents' perceptions of the severity of their child's problem could be inferred from a number of different areas such as the level of initial concern, their emotional response, their concern for the future, including the consequences and impact of their child's problems; and their perceptions of control. Differences between groups were apparent across the majority of these areas, with parents in the CA group perceiving their child's problem to be of greater severity. The type of SLCN seen was comparable across groups, although having an additional diagnosis such as an autism spectrum disorder or developmental delay featured more in the CA group. This could also contribute to the perception of greater severity or at least in perceiving more symptoms. Perceptions of severity have been shown to have a greater association with outcome than objective clinical indicators of severity (Cameron & Moss-Morris, 2004) and parental judgement of severity was associated with significantly better adherence to their medical treatments in children with less serious conditions but whose parents judged them to be in poorer health (DiMatteo et al., 2007). Perceived problem severity is also associated with seeking contact with formal services (Featherstone &

Broadhurst, 2003). In the present study parental perceptions of the severity of their child's SLCN may have been a motivating factor to participating in SLT.

Illness perceptions general: Parents in both groups suggested that they had little control over their child's SLCN and in the CA group many identified both immediate and future consequences of SLCN. The immediate consequences of SLCN included affecting their child's peer relationships and in the future, social relationships, educational achievement and employability. These concerns have also been reported in other studies of children with SLCN and their parents (Langevin et al., 2010; Lindsay & Dockrell, 2004; Lyons et al., 2010). Parents in the present study did not directly discuss their views on how long their child's problem would last or whether it was acute, cyclical or chronic. However, ongoing concern over the future for their child, even after discharge from SLT was a feature of the CA group indicating that these parents considered the problem to be at least of longer duration if not chronic. Although there is uncertainty in interpreting the symptoms and labels these parents gave to their child's SLCN, having a strong illness identity has been associated with viewing the illness or problem as uncontrollable, chronic and with serious consequences (Hagger & Orbell, 2003).

Social Cognitive Theory (SCT): Self-efficacy (SE): Parents also made comments about their confidence and belief in their ability to work on communication skills with their child. Parents in the CA group reported being confident in carrying out the home-based recommendations, seemingly believing themselves capable. In contrast a lack of confidence was apparent in the IA group. Confidence in the specific tasks of following recommendations has not previously been reported in SLT. SE beliefs, that is one's belief in our ability to succeed in a particular task or situation, are an important in motivating an individual towards a desired outcome and a determinant of both personal and treatment control beliefs (Horne & Weinman, 2002b; Moss-Morris et al., 2002).

Parents did not comment on their parenting skills directly but inferences could be drawn from the interviews. In the CA group the specific self-blame attributions made, such as not talking enough, may reflect a lack of SE in certain aspects of their parenting. Certainly parents of children with SLCN themselves have previously made this association between parental competence and self-blame (Glogowska & Campbell 2004). These parents also appeared empowered by SLT citing benefits such as improving their parenting, which may have increased their sense of control of their child's problem and their confidence as parents. Conversely parents in the IA group appeared to have greater confidence in helping their child

themselves, given their preference to help their child first before SLT. This may however, be related to their reduced understanding of the SLT practice or a mismatch between their beliefs and the treatment offered. Self-efficacy beliefs in the domain of parenting, along with control beliefs, have been shown to be associated with child negative behaviour in parents of children who have an intellectual disability (Hassall & Rose, 2005). Their review indicated that parenting self-efficacy may be adversely affected by increased behaviour problems in their child, and that lower self-efficacy is associated with higher parent distress. Parents in the CA group expressed more negative emotions and perceived their child's difficulties as severe but it remains unclear if the presence of behaviour difficulties in their child was a contributory factor.

Therapeutic Alliance and Treatment beliefs: The nature of the specific self-blame attributions by parents in the CA group is also relevant to understanding the differences in the level of attendance. Spending time and talking to your child are directly linked to the specific types of behaviour that would be encouraged in parents by SLTherapists, for example in PCI interventions (Roberts & Kaiser 2011). These parents may have been more motivated to participate as they believed that not only did they in part cause their child's problem, but potentially it was within their power to change and that SLT offered a solution congruent with their beliefs. The nature of a specific causal attribution has been found to be associated with subsequent changes in health behaviour and treatment choice in many clinical areas (e.g. Cameron & Moss-Morris, 2004; Petrie & Weinman, 2006; Weinman, Petrie, Sharpe, & Walker, 2000). Parents' who believe food allergies are a significant causal factor are more likely to utilise special diets, vitamins and detoxification treatments for their child with autism (Dardennes et al., 2011). Equally, lack of exercise as a causal belief was associated with changes in exercise behaviour in adults following a myocardial infarction (Weinman et al., 2000). These types of beliefs may also influence the therapeutic alliance, in particular the agreement with tasks associated with an intervention (Bordin 1979). This may suggest that therapeutic alliance was greater in parents in the CA group.

Summary: The pattern of differences between groups could suggest that parents who recognise their child's problems, believe they are severe and actively seek a referral, and who believe that their own role is important both in terms of being part of the cause and also the solution and that the treatment matches the solution, are more likely to engage in SLT intervention. Some degree of self-doubt about parenting skills may also be a motivating factor for adherence.

Demographic differences:

In addition to differences in parent cognitions across the two groups there were also some variations in socio-demographic factors and the nature of service delivery, which may also be contributory factors to the levels of attendance observed. The CA group included more participants who were homemakers (all mothers), part of a two-parent family and were educated to degree level than the IA group. There were also more full time workers and fewer part-time workers in the CA group. A tentative conclusion maybe that parents in the CA group had a higher socio-economic status (SES), although a specific measure of SES was not used. Lower levels of deprivation have been shown to predict better attendance in parents of children with ASD when a composite SES score, representing caregiver occupation and education, was used (Carr et al., 2015). Caution is required in applying these results to the present research due the lack of an objective indicator of SES in this study. In addition SES is often operationalised as education, occupation and income but these three components can relate differently to different measures of health (Geyer, Hemström, Peter, & Vågerö, 2006).

Differences in ethnicity across the two groups were also observed, with a greater representation of black ethnic groups in the IA group. In addition, although the number of monolingual households was similar relative to group size, the language was more likely to be non-English in the IA group. Adequate proficiency in spoken English was required in the present study; however, language barriers may have contributed to parents' failure to understand treatment. The implications of ethnicity on attendance is equivocal with some studies reporting lower attendance in minority groups (Sherman et al., 2009) and others finding no effect (Arnold et al., 2003) but without clear reasons why. Similar findings exist for ethnicity non-adherence relationships (Haine-Schlagel & Walsh, 2015). In SLT cross-cultural differences in beliefs about language development, parenting practices and SLT interventions have been described (Johnston & Wong 2002; Law, 2000; Simmons & Johnston 2007) which may have the potential to influence the therapeutic alliance and affecting participation.

The nature of service delivery differed between groups. Children in the CA group most commonly worked with a single therapist whilst the IA group who typically worked with more. All children received a range of interventions, though only children in the IA group received intervention in a nursery setting. The reason for this difference is not clear but anecdotally SLTherapists will consider delivering therapy in a setting such as a nursery when they perceive,

for whatever reason, that parents are finding participation difficult. It is also possible that SLTherapists were finding engagement with these parents difficult, which resulted in multiple therapists being involved. SLTherapists were not interviewed for the present study but non-attendance has been associated with negative perceptions of patients by other health professionals (Mitchell & Selmes, 2007).

5.5.4 Limitations

The first major limitation arises from the loss of all original data following a significant IT incident. As only a single user license was purchased, the software programme used for the analysis was only located on the hard drive of a single computer and, as the data files were believed to be integrated into the software, no backup was available. All data was lost when, without prior notice, the departmental IT Support Analyst wiped the hard drives of all computers. The original transcripts had previously been deleted as per ethical guidance. The loss of this data affects the credibility of the study. However, to support an audit trail, print outs of earlier versions of the analysis and drafts of the results section (including approximately 60% more direct quotes) are available, providing data reduction, analysis, reconstruction and synthesis products with additional examples of raw data. To limit the reoccurrence of such an event three actions followed: 1. a record of software with single user licenses was created, 2. a protocol was introduced whereby notice was given of any changes to hardware or software, and 3. the researcher increased her vigilance of ensuring regular backups of all data. The version of the Framework software used (v1.1) has now been superseded and is no longer available.

Qualitative research is interpretative and ethnographic in nature; its aim is to capture the depth and range of experiences of a given group of participants and is not intended to be representative (Gale et al., 2013). Therefore it cannot be argued that the results of this study are generalisable, although universal transferability is rare regardless of research design (Malterud, 2001). That said, many of the observations accord with other research in SLT conferring some validity to the data. In addition research outside the field lends some tentative support to how the pattern of observations fit with theories relevant to the study of participation.

In qualitative research the researcher is the primary instrument through which all data is mediated. This qualitative data is therefore rooted in the preconceptions, experiences and beliefs of the researcher highlighting the second major limitation of researcher subjectivity (Malterud, 2001). Added to this is the inexperience of the researcher, although well supported by a supervisor (Dr E. Grunfeld) with extensive experience in qualitative research. Efforts were made by the researcher to challenge any preconceptions by looking for competing conclusions, and to increase validity through an external researcher validating codes (Malterud, 2001). The risk of bias could have been reduced further if the researcher was blinded to group membership. Blinding was not undertaken as to ensure a sufficient number of participants with low levels of attendance (anticipated to be harder to recruit to), categorisation of participants into groups was required prior to recruitment and by the researcher. This was borne out and resulted in the original three groups that were initially envisaged, reduced to two. A further technique for reducing bias is to check back the findings with participants (Silverman, 1997); this was also not done due to concerns about participant burden and risk of participants being lost to follow up. The researcher acknowledges the risk of subjectivity of in the interpretation of this data.

Through its constant comparative approach, the Framework method allows for comparisons between groups (Gale et al., 2013; Ritchie & Lewis 2003). Themes are compared and contrasted; however, it is not certain that these themes represent single constructs making direct comparisons problematic.

The final limitation is uncertainty over whether data saturation was reached. It is recommended that sampling is done stepwise to allow for concurrent data analysis. Recruitment continues until the analysis indicates that no new information is forthcoming (Malterud 2001). The recruitment process attempted to facilitate this by sending out invitations in batches, but, as the researcher was part-time, competing demands interfered with the ability to analyse the data synchronous with recruitment and so all data was analysed together at the end of recruitment.

Conclusion

This study suggests that parents can be active problem solvers when approaching their child's difficulties, they make decisions about their child's problem such as to attend or not and are not passive recipients of therapy. Given the qualitative nature of this study it is not possible to draw conclusions as to what motivates a parent to attend but the results suggest that parental perceptions about their child's problem, their emotional response, their self-efficacy to help their child and views of the therapeutic alliance are important. Parenting self-efficacy may also be a contributory factor, although this is less clear. In addition the pattern of their responses lends some support to the applicability of the various theoretical models associated with participation: SRM, SCT, and Therapeutic Alliance. A further model, Barriers to Treatment (Kazdin et al., 1997), proposes that it is the number of barriers rather than the type which is important in predicting attendance. Most parents did experience barriers; however, as it is thought that it is the total number of barriers that may influence participation, design limitations meant that it was not possible to calculate totals and make inferences. Although the implication of this observation remains unknown, it was considered important to retain this element in the main study. Satisfaction with SLT appeared to be related to expectations so it may be important to include an evaluation of both. The observed differences between the two groups in demographics, child characteristics and ethnicity also warrant inclusion in the main study.

The main study in this thesis will aim to identify the levels of attendance and adherence to SLT and explore how parental factors such as beliefs, experience of treatment and personal circumstances relate to adherence and attendance. Whether these factors relate to child outcome will also be evaluated.

CHAPTER 6

Measurement of Constructs

Overview of Chapter

This Chapter describes the identification and selection of the measures for use in the main study that would not be used as standard practice within SLT departments. Measures are identified that are relevant for assessing the contribution of parental factors such as beliefs (illness perceptions, self-efficacy); experience of treatment (expectations of treatment, therapeutic alliance, satisfaction); personal circumstances (family functioning, SES, practical barriers) and child characteristics to attendance and adherence. Measures for the primary outcomes are also introduced. SLT measures of SLCN, including standardised measures, will be described in Chapter 8. Scales developed specifically for this research (self-efficacy scale) or that were modified significantly (illness perceptions questionnaire-revised) are introduced here but described fully in the subsequent pilot study (Chapter 7). This also applies to constructs where two equally acceptable measures were being considered (adherence and satisfaction).

6.1 Background

Both the review of the literature and the qualitative study (Chapter 5) indicate that a number of factors may be relevant in the study of participation in SLT. These can be broadly categorised into parental beliefs, parental experiences of treatment, parent personal circumstances and child characteristics. Table 6-1 summarises the independent variables of interest under these categories, as well as the dependent variables. The measurement of the main outcome variable participation, includes both attendance data and adherence to recommendations. These will also be used as independent variables when examining relationships with child outcome.

Table 6-1 Summary of variables

Independent variables	Dependent variables
<i>Parental Beliefs:</i> illness perceptions, self-efficacy,	Adherence
<i>Parental Experiences of Treatment:</i>	Attendance
Expectations of treatment/outcome,	Child Outcome
Therapeutic Alliance, Satisfaction	
<i>Parent Personal Circumstances:</i>	
demographics, family functioning, practical barriers	
<i>Child Characteristics:</i> severity, SLCN,	

Measures were identified through database searches (Embase, Medline, PsychInfo, CINAHL). Preference was given to measures that were used within SLT and/or within psychological treatment, and with parents of children. Self-rated rather than therapist-rated measures were considered preferable to minimise burden on the SLT department.

6.2 Dependent Variables

6.2.1 Adherence

Measures of homework completion are the most common subjective scales used across the adherence literature and many are designed for a particular study (Haine-Schlagel & Walsh, 2015). Three potential measures were identified to use with parents of children with SLCN.

These were the Homework Rating Scale II (HRS), used in psychological treatment with adults (Kazantzis, Deane, Ronan, & L'Abate, 2003), the Adherence Telephone Interview Form (ATIF) (MacNaughton & Rodrigue, 2001) and its later modified form (M-ATIF) (Dreyer et al., 2010). Both versions of the ATIF were used with parents of children referred for psychological intervention. Despite the HRS II being developed for use with adults, it was also being piloted with parents of children engaging in Cognitive Behavioural Treatment (T.Marsh, personal communication) and thus appeared relevant to the present study. As both versions of the ATIF and the HRS II were considered suitable, piloting was recommended (Chapter 7).

6.2.2 Non-attendance

All appointments are processed via an electronic patient record system (EPRS). SLTherapists are required to record outcomes following appointments, including attendance/non-attendance and reasons for non-attendance. This data is captured in two ways using separate actions, the first uses simple actions and codes via an EPRS and secondly, clinicians record the same information as a part of a clinical progress note. Data extraction of codes is dependent the availability of an NHS employed data analyst, which was the approach used to identify the groups in the qualitative study (Chapter 5). Obtaining the data for the cohort study would involve a greater time commitment from the analyst due to the duration and staggered approach to recruitment. This time commitment, alongside a significant reorganisation of local NHS Trusts at the time, meant that an analyst could not be made available. Instead, the researcher manually searched patient records and identified appointments offered, the outcome and appointments missed without notice. This provided a record of non-attendance.

6.2.3 Child outcome

A measure was required that would allow comparisons of outcomes across different child needs and treatments. At this time the local service, following the merger of two community SLT departments, was in the process of reviewing their approach to outcome measurement and, in conjunction with the researcher, concluded with a recommendation for the introduction of Goal Attainment Scaling (GAS) (Kiresuk, Smith, & Cardillo, 1994).

GAS is a method that measures an individual's progress towards a pre-specified target. Clinicians set individual goals at the beginning of an intervention that are specific, measurable,

acceptable, relevant and time related (SMART), measuring progress using a universal rating system with a 5-point scale (Kiresuk et al., 1994). Six and seven point scales have also been used but were not used here (Duco Steenbeek, Ketelaar, Galama, & Gorter, 2007). An example of a GAS outcome, completed for an individual child, can be seen in Table 6-2. An individual may have more than one scale per intervention cycle and these can be combined and converted into a T-score. T- scores greater than fifty indicate that achieved goals (as the mean of a large number of converted scales) would be expected to converge on 50 (SD 10) (Sherman 1994). Researchers have provided some support for these assumptions (e.g. Cardillo and Smith, 1994a), although criticisms are also presented by others (e.g. Steenbeek et al., 2007) – see below).

Table 6-2 Example of a GAS form completed by a SLTherapist

Level of expected outcome	Description	Monitoring of progress (including date of monitoring)				
		1 30/01/15	2 6/2/15	3 13/2/15	4 20/2/15	5 20/4/15
+ 2 Much more than expected	[name] use single words to request for activities.					
+1 More than expected	[name] will vocalise alongside gesture or sign to request activities.					
0 Most likely outcome	[name] will reach, gesture or sign to request activities.					x
-1 Current level	[name] will smile at times in request for activities, or to show enjoyment.				x	
-2 Less than expected	[name] will run around and refuse to co-operate with any activity.	DNA	x	x		

There are a number of positive qualities about GAS including being child-centred, providing clear goals, being sensitive to changes and socially valid to parents and clinicians alike, even though it can be time consuming (Steenbeek et al., 2007). Steenbeek and colleagues (2007) reviewed the GAS literature in paediatric rehabilitation; studies were included if they a) aimed to assess the psychometric properties of GAS and b) in studies where GAS was used to measure treatment effect. Overall, nine studies were located, three meeting the criteria for a) and six for b). The authors concluded that despite the promise of GAS, the reliability and validity of the scales was ambiguous perhaps due to the idiosyncratic nature of the approach. Across the three studies meeting the criteria for a), inter-rater reliability was reported as acceptable, concurrent validity was low in two of the studies; no study reported on content validity. The author also raised concerns about T scores as studies treated the data as interval

rather than ordinal. Finally, the original authors of GAS (Kiresuk et al., 1994), proposed that training was required to use this approach, but there was little evidence of this in the included studies (Steenbeek et al., 2007). These conclusions are based on a small sample and reflect the limited literature on GAS with children at that time.

Despite these cautions and small number of studies available for review, GAS is widely used across adults and the elderly and increasingly in child populations (Steenbeek, Gorter, Ketelaar, Galama, & Lindeman, 2011). It is considered to have greater sensitivity to change than standardised measures particularly in heterogeneous populations. There is also supportive evidence for its use in SLT both uni-professionally (e.g. Schlosser, 2004) and in the context of a multi-disciplinary team (e.g. Steenbeek, Ketelaar, Galama, & Gorter, 2008).

Where possible, these concerns about GAS were responded to for the benefit of this study. Although not following the exact same training procedure as Steenbeek and colleagues (2008), all SLTherapists in the department attended 2, two hour workshops delivered by a senior SLTherapist experienced in the use of GAS. The workshops were videoed to allow any new staff to participate in the same training process. Individuals were asked to formulate GAS targets for individual children and which were then discussed both individually and as a group in the second session. Following training and to provide continued guidance, SLTherapists were asked to regularly bring GAS forms to supervision with senior staff. GAS 'champions' were identified across the teams to provide accessible support. The service had been consistently using GAS for approximately three months prior to the start of the study and an audit of its use was conducted in December 2014 (Appendix 6.1).

6.3 Independent variables

6.3.1 Parental Beliefs: illness perceptions, self-efficacy,

6.3.1.1 Illness perceptions:

A range of measures exist for the measurement of illness perceptions with the majority assessing single components such as 'control' or 'causal beliefs'; however, the dominant measure of illness perceptions is the Illness Perceptions Questionnaire (IPQ) (Weinman et al., 1996) and its revision, the IPQ-R (Moss-Morris et al., 2002; Scharloo & Kaptein, 2013). Weinman et al (1996) recognised the need to develop a theoretically and psychometrically

driven measure of illness perceptions in response to the increasing interest in patients' representations of illness as described by Leventhal's Self-regulation model (SRM). The IPQ incorporated five SRM domains: identity, cause, time-line, consequences and cure/control (Weinman et al., 1996). It was developed for use with chronic illnesses and validated in rheumatoid arthritis, diabetes and chronic pain samples.

The subsequent revision (IPQ-R) increased and refined the represented domains and was developed with eight illness groups (rheumatoid arthritis, type II diabetes, asthma, chronic pain, acute pain, multiple sclerosis, myocardial infarction, HIV) (Moss-Morris et al., 2002). The revised scale included eight reliable subscales ($\alpha = .79$ to $.89$): timeline acute/chronic, time-line cyclical, personal control, treatment control, consequences and emotional representations domains, confirmed by factor analysis and together explaining 64% of the variance. The cause scale was extended in this version using attributional items generated from illness specific studies using the IPQ. Factor analysis of the cause scale revealed four domains labelled: psychological, risk factor attributions, immune attributions and accident/chance attributions which also showed adequate internal consistency ($\alpha = .67$ to $.86$). The identity scale in the revised version retained the original twelve commonly experienced symptoms and added two further: sore throat and wheeziness. The rating system was altered to reflect the original concept of 'identity' i.e. the process of matching symptoms to an illness label, with participants now asked to rate first if the symptom is present and then if it is related to their illness. Overall the IPQ-R improved the psychometric quality of the measure in comparison to the IPQ; both measures were stable over time (3weeks to 6 months).

In recognition of the unique and individual characteristics of different populations and illnesses, the authors of both versions recommend adaptations, particularly for the identity and cause scales. The IPQ-R has been used with a range of medical illnesses such as asthma (Horne & Weinman, 2002a), diabetes (Mc Sharry, Moss-Morris, & Kendrick, 2011) and musculoskeletal disorders e.g. fibromyalgia (van Wilgen, van Ittersum, Kaptein, & van Wijhe, 2008). Versions have been created for children between the ages of seven and twelve years of age (Walker, Papadopoulos, Lipton, & Hussein, 2006) for relatives of patients with mental health problems (Lobban et al., 2005) and for parents of children with autism (Al Anbar et al., 2010) demonstrating the adaptability of the tool.

The revised version was identified as the measure of choice in capturing parents' perceptions of their child's SLCN. The modification of the IPQ-R, including revisions to increase its relevance to SLCN, is described in chapter 7, where the measure was also piloted.

6.3.1.2 Self-efficacy:

Self-efficacy is domain specific (Bandura 1979) and evidence from the literature review and qualitative study suggests that two areas may be relevant to the study of participation in SLT: confidence in following SLT recommendations and confidence in one's parenting skills.

Self-efficacy in following SLT Recommendations: A literature search did not reveal any self-efficacy measure pertaining to completing recommendations or homework in SLT. Self-efficacy scales are available in other fields. In diabetes for example, one measure follows the format "How sure are you that you can do each of the following, almost all the time?" followed by statements such as 'Do your blood sugar checks even when you are really busy' (Iannotti et al., 2006). In physiotherapy, alternative formats have been used for example, one scale began with an introductory statement 'I am confident that I can perform a planned exercise even if..' and followed by a twelve statements such as '..I am tired' or '..I am tense' (Fuchs, Wegner, Schwarzer, in Schwarzer 1993). Schwarzer and Renner (2009) have also developed a number of health-specific self-efficacy scales including nutrition, physical exercise and alcohol. A scale specific to a particular domain is necessary as generalised measures or those from other fields may have little or no relevance to the area being studied (Bandura 2006). To this end the development of a SLT specific measure of self-efficacy was prudent and is described and piloted in the following Chapter (7).

Self-efficacy in parenting skills: A literature search identified two measures of potential relevance for this study: the Self-efficacy for Parenting Tasks Index (SEPTI) (Coleman & Karraker, 2000) and the Parents Sense of Competence Scale (PSOC) (Ohan, Leung, & Johnston, 2000).

The sixteen-item PSOC (Ohan et al., 2000) was designed to assess parents' satisfaction and confidence in their own parenting using a six-point self-rated Likert scale. A total score provides an overall rating categorised into low, medium or high self-confidence. Statements such as 'The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired' and 'I meet my own personal

expectations for expertise in caring for my child.' are typically generic rather than relating to a specific aspect of a parenting skill. The reliability and validity of the PSOC has been described and three subfactors identified within the overall scale through factor analysis (e.g. Rogers & Matthews, 2004). In Rogers and Matthew's large study (N(mothers)=849), the three factor solution explained 52% of the variance and the internal consistency of the factors ranged from questionable to good ($\alpha = .58$ to $.78$). Concurrent validity for a satisfaction factor was confirmed but not so for the efficacy and interest factors. Gilmore & Cuskelly (2009) also provided evidence of three factors: satisfaction, confidence and interest in parenting, with a large non-clinical sample (N(mothers)= 586). Internal consistency of the factors in this study ranged from poor to questionable ($\alpha = .44$ to $.68$). This scale was not selected for use given the unsatisfactory concurrent validity of the efficacy factor, questionable internal reliability and in the generic nature of references to parenting.

The SEPTI is a self-rated measure of parents' confidence in their parenting skills across seven domains considered most relevant to parenting a child. There are three versions of this measure: SEPTI (age range 5-12 years)(Coleman & Karraker, 2000)), SEPTI-TS (toddler scale, age range 19-24 months) (Coleman & Karraker, 2003) and the short form SEPTI-TS (age range 17-48 months (van Rijen et al., 2014). Given the age range of children in this study, the short form SEPTI-TS would be suitable; however, a number of domains potentially relevant to parenting a child with SLCN are removed in this version (teach, emotional availability). Specific items relating to feeding were also removed which could be important given the prevalence of fussy eating in children with ASD (Bandini et al., 2010) and who are likely to be included (diagnosed/undiagnosed) in the sample. As the children in this study, by their inclusion, have delayed speech and language the content the SEPTI-TS (Coleman & Karraker, 2003) was relevant despite being designed for children up to two years of age.

The original measure included seven domains: Emotional availability ("I am usually willing to stop what I'm doing and cuddle my child when he/she seems to need affection"), protection ("I have my home arranged to prevent as many accidents as possible with my toddler"), nurturance ("I think my child knows by my behaviour how much I really adore him/her"), discipline ("Setting limits for my child is relatively easy for me"), play ("I am a fun playmate for my child"), teaching ("Sitting down regularly with my child to read or do some other one-on-one activity is not difficult for me ") and instrumental care ("I am able to provide my child with a comfortable amount of daily structure"). Parents rate their agreement on a six point Likert scale with higher scores indicative of greater confidence in one's own parenting skills.

Adequate reliability was demonstrated for the majority of subscales by the original authors (Cronbach's $\alpha = .67$ to $.92$). Instrumental Care demonstrated questionable consistency ($\alpha = .60$) and the Protection subscale had poor internal consistency ($\alpha = .53$).

All domains with the exception of the protection subscales were considered relevant to parenting a child with SLCN and associated interventions. For example, parent child interaction treatments would encourage an increase in the frequency of interactions and the responsiveness of the parent (Roberts & Kaiser, 2011), which could be related to the emotional availability and nurturance subscales. For the other domains SLTherapists will also support parents to use play and teaching strategies to develop child skills and, given the prevalence of behaviour difficulties, it is not uncommon for clinicians to provide advice on behaviour management (discipline domain). Finally as children with SLCN include those with other developmental conditions, including autism and intellectual disability (Bishop and Norbury 2009), problematic sleep routines and eating difficulties are not uncommon (Dominick et al., 2007) (instrumental care domain), although SLTherapists may not always directly intervene in these areas. In contrast, safety (protection subscale) is not a primary concern in routine SLT interventions unless safeguarding concerns are raised and, from an ethical stand point it, appeared appropriate to exclude this subscale. No other changes were made.

The SEPTI-TS, minus the Protection subscale, was therefore selected as the measure of choice when aiming to be over inclusive in an explorative study such as this (Appendix 6.2).

6.3.2 Parental Experiences of Treatment: Therapeutic Alliance (TA), Satisfaction, Expectations

6.3.2.1 Therapeutic Alliance:

Two measures were identified from a search of the literature, and in particular from an empirical review of the measurement of therapeutic alliance (Elvins & Green, 2008). In their review, the authors located and reported on thirty three measures of TA including those designed for adult, child and carer audiences. Measures differed in their theoretical origins, on which aspect of the alliance they were measuring and the number of items in the scales varied widely, reflecting the lack of an overall consensus model of alliance. For the present study a measure was required that was suitable for measuring parent alliance in the context of child treatment. Two potential measures were initially identified: the Empathy and Understanding

Questionnaire (EUQ) (Green, 2006) as it was developed for use with parents receiving outpatient psychological treatment, and the Working Alliance Inventory (WAI) (Horvath & Greenberg, 1989) as it has been adapted for use with parents (e.g. Hawley & Garland, 2008; Kazdin et al., 2005).

The EUQ (Green, 2006) is a self-report measure designed to capture both adolescents and parents' views on the alliance in psychotherapy and follows the tradition of Hougard's development of Bordin's work (Hougard 1994). Single questions cover an individual's understanding of the rationale for treatment, their experience of empathy from a clinician, of collaboration and of the treatment process. Clinicians are also asked to predict families' responses and to rate their own empathy to capture all contributions of the alliance (Green 1996). The initial psychometric properties of the scale were described as acceptable in a pilot study (Green 2006), although this measure has not been widely used (Elvins & Green 2008). This measure was not selected due to its conceptual roots, the use of single items to represent different aspects of TA and its low usage across the literature. The expectation of multiple informants, whilst ideal, led to concerns of overburden for SLTherapists.

The WAI is a thirty-six item, self-report instrument that was developed to reflect Bordin's view of the therapeutic alliance including the three components of task, bond and goal alliance (Horvath & Greenberg, 1989). The original measure and its components were internally consistent with Cronbach alphas of .93 for the overall score and Cronbach alphas of .85 to .88 for the subscales. Subsequent revisions led to two short form versions WAI-S (Tracey & Kokotovic, 1989) and WAI-SR (Hatcher & Gillaspay, 2006). These measures have been used widely in a number of contexts including psychotherapy (e.g. Hukkelberg & Ogden, 2016), counselling (e.g. Duff & Bedi, 2010) and psychological treatment (e.g. Knaevelsrud & Maercker, 2007). The WAI-S (Tracey & Kokotovic, 1989) was selected over the more recent WAI-SR as the language used was more suited to the SLT context, requiring fewer modifications. For example the WAI-SR contains the statement "I feel ___ cares about me even when I do things he/she does not approve of." which does not reflect the typical nature of the relationship between a parent and a SLTherapist.

In producing the WAI-S, the four highest loading items from each of the original subscales were selected, reducing the original 36 item measure to 12 (Tracey & Kokotovic, 1989). As with the WAI items are scored on a 7-point scale (minimum score 7, maximum 84) with a higher score indicating higher positive ratings of the alliance. Validity for the measure was supported

through confirmatory factor analysis and using three goodness of fit indices. A two level factor structure was confirmed with the first order factors being the task, bond, goal domains and a second order dimension of general alliance. Reliability of the three components and the overall scale was excellent: task Cronbach $\alpha = .90$, bond Cronbach $\alpha = .92$, goal Cronbach $\alpha = .90$ and general alliance Cronbach $\alpha = .98$. Task statements include: 'What I am doing in therapy gives me new ways of looking at my problem.' Bond statements include '_____ and I trust one another.' An example of a Goal statement is: '6. _____ and I are working towards mutually agreed upon goals.'

Minor modifications were made to the wording of the measure for use in this context, such as changing 'my' to 'my child's', for example "1. _____ and I agree about the things I will need to do in therapy to help improve **my** situation." changed to "1. _____ and I agree about the things I will need to do in therapy to help improve **my child's** situation." In a similar vein 'help me' was modified to 'help me and my child' (item 5) and an additional item to "3. I believe _____ likes me." was added: "3a. I believe _____ likes my child." The modified measure can be found in appendix 6.3.

6.3.2.2 Expectations of treatment

Parents Expectancies for Therapy Scale (PETS)(Nock & Kazdin, 2001): This questionnaire was designed to measure parents' expectations of change before child psychotherapy intervention. The original 25-item version has three components confirmed by factor analysis: credibility (13 items e.g. "I believe that my child will improve quickly."), child improvement (6 items e.g. "How much do you believe the treatment will help you in being a parent?") and parent involvement (6 items, e.g. "How much of a role do you believe that you will have in your child's treatment?"). Parents were asked to rate their answers on a five point scale (minimum score of 25 , maximum 125); higher scores indicate greater positive expectations of therapy. Good reliability was reported for the full measure (Cronbach's $\alpha = 0.79$) as well as the components of credibility and child improvement (Cronbach's $\alpha = .72, .75$ respectively). The reliability for the Parent involvement subscale was less optimal (Cronbach's $\alpha = .56$).

For the present study, modifications were made to the measure to complement the nature of SLT interventions as opposed to child psychotherapy. Five items were deleted from the original questionnaire due to lack of relevance for service delivery and intervention in SLT.

Three of the deleted items came from the credibility domain and two from the parental involvement domain.

- 12) I believe that my child will mostly be talking about his/ her feelings in therapy, rather than learning how to behave differently.
- 21) I believe that the therapist will call me during the week.
- 22) I believe these outside phone calls will help improve my child's behavior.
- 23) How will this treatment compare in effectiveness with having the child talk over the problem with a counselor at school?
- 24) How would this treatment compare in effectiveness with medical treatment (e.g., medication) for the problem?

Minor changes in wording were also made to enhance the relevance to SLT, for example: '1) How much do you believe that the treatment at the clinic will help to better control his or her behavior?' became: 'How much do you believe that the treatment at the clinic will help your child's communication skills?' and '10) I believe sessions will be once a week.' Became 'I believe sessions will be once a week for a certain number of weeks.' The adapted 20 item version can be found in appendix 6.4.

6.3.2.3 Satisfaction with Services

A measure was required to evaluate parents' satisfaction with SLT services. Initial searches for scales specific to SLT identified the Consumer Satisfaction Parent Questionnaire (CSPQ) (Grela & Illerbrun, 1998); however, although published, it had not been psychometrically evaluated. The CSPQ was developed specifically for a study evaluating pre-school SLT services in Canada. The description of child assessment and intervention that was being evaluated was similar to the service offered to many families within the present study. For example parents in their study were offered at least four weeks individual parent training sessions focused on parent child interaction techniques, and in the present SLT service the same is offered either individually or in a group. Extending the search to more generic patient satisfaction measures located the Client Satisfaction Questionnaire (CSQ-8; Attkisson & Greenfield, 2004). The CSQ8 is a single factor measure representing an estimate of general satisfaction (Attkisson & Greenfield, 2004). A reliable measure (Cronbach α range from .83 to .93) it is widely used across different services and populations (Hodges, Markward, Keele, & Evans, 2003). It has also

been used in a study of parent training attendance (Glassman 2013 unpublished doctoral dissertation).

Derived from a similar service, the CSPQ was highly relevant for use within SLT, although unvalidated. The CSQ8 is a widely used and well validated measure of satisfaction. Piloting both measures was therefore appropriate to assist with selection (Chapter 7).

6.3.3 Parent Personal Circumstances: demographics, family functioning, practical barriers

6.3.3.1 Demographics

Demographic features that have been variously shown to be associated with non-participation include higher deprivation (e.g. Nock & Ferritzer 2005), ethnicity (e.g. Sherman et al., 2009) and age, (e.g. Milne et al., 2014). Indices of deprivation or socio-economic status (SES) can vary but multiple perspectives are recommended aiming to capture both global (e.g. area of residence using postcodes) and individual social disadvantage such as education, employment or income, particularly as different metrics can lead to different results (Geyer et al., 2006). Nock & Ferritzer's review (2005) cited a number of studies reporting the relationships between indices of SES and participation. In these studies a number of factors were related to non-participation including urban residence, minority status, single-parent status, and Medicaid status (e.g. Armbruster & Schwab-Stone, 1994; Kendall & Sugarman, 1997). Obtaining a range of demographic information was therefore indicated and included the following data: parents: age, marital status, education level, ethnicity, employment: status and job title, postcode; and for the children: date of birth, place in the family and ethnicity. See appendix 6.5 for the demographics form used to collect this data.

6.3.3.2 Family Functioning

Individual measures of parenting stress, for example the Parenting Stress Index (Lloyd & Abidin 1985), and family functioning (Bloom, 1985) are available. In this exploratory study, when consideration was given to the ethics of obtaining unnecessary detail about negative family experiences or stressors, it was considered sufficient to ask 'soft' questions. The Family Life Questionnaire (FLQ) (Green, personal communication) was made available and met the requirements for this research. It should be noted that the authors were considering changing

the name of the FLQ to the Autism Family Experience Questionnaire but the original name was retained to avoid confusion.

The FLQ is a measure of family and child functioning developed through extensive and iterative consultation and collaboration with parents of children with an autism spectrum disorder (ASD). Its intended use was as an outcome measure following psycho-social communication interventions in ASD; aiming to encapsulate functionally important changes in family life. Although designed for an ASD population, it remains relevant for SLCN due to the overlap of language and communication impairments across both groups (Bishop, 2010). The sample within this study is also likely to have a proportion of children with diagnosed and undiagnosed ASD.

The questionnaire is divided into four domains (table 6-4) referring to the experience of having a child with autism, family life, the child's development (including understanding and social relationships) and also symptoms (feelings and behaviour). The child functioning domains including child behaviour were retained as an additional measure of child severity (see also child characteristics section below). These domains demonstrated a moderate to strong association with the Vineland Adaptive Behavior Scale (VABS), dependent on the timing of measurement so at baseline $r=-0.47$ ($p<0.001$, $n=143$) and end point $r=-0.57$ ($p<0.001$, $n=134$), and provided support for convergent validity. Examples from each include e.g. "I feel I know how to help my child progress" (Experience of being a parent of a child with Autism), "Family life is a battle" (Family life), "My child can let me know when he/ she is hurt" (Child development) and "My child is angry" (Child symptoms). Items are rated on a scale of 1-5, with (1 = 'always', 5 = "never"). Once any negatively worded items are reverse scored, a higher score indicates poorer child and family functioning and a lower score would suggest better functioning in the child and family (minimum possible total score is 48, maximum possible is 240). Factor analysis of the original measure was not achieved (Green, personal communication). This would not be considered unusual in a measure derived from parent experience where there is no apriori theoretical basis for the constructs (Eiser & Morse, 2001).

Table 6-3 Original domains of the FLQ

Domain	Question numbers	Minimum and maximum score
Experience of being a parent	Q1-Q13	13-65
Family Life	Q14-Q22	9-45
Child Development		
Child Development	Q23-Q30	8-40
Child Understanding	Q31-Q33	3-15
Child Social Relationships	Q46-Q48	3-15
Child symptoms		
Child Feelings	Q34-Q40	7-35
Child Behaviour	Q41-Q45	5-25
Total AFEQ score	Q1-Q48	48-240

Only one modification was made: changing the heading 'Experience of being a parent of a child with **autism**' to 'experience of being a parent of a child with **Speech, Language, Communication Needs (SLCN)**' (appendix 6.6).

6.3.3.3 Barriers: Barriers to Treatment Participation (BTPS) (Kazdin, Holland, Crowley, & Breton, 1997)

The BTPS was selected to evaluate the impact of barriers on participation in SLT as it is derived from the authors' theoretical perspective about the cumulative effects of multiple burdens on treatment attendance.

This self-report measure was designed for use with parents of children and adolescents participating in psychological therapies to identify reasons for dropping out of intervention. It was developed through an iterative focus group process with therapists with direct experience of patient drop out. In the first section (44 items) four themes emerged that resulted in the a priori subscales of 'competing activities/life stressors', 'relevance of treatment', 'relationship with therapist' and 'treatment issues'. The items were rated on a 5-point scale, with 1 being 'never a problem' and 5 very often a problem'. These subscales were not confirmed with factor analysis and the scale was best represented by a single factor. This single factor 'total barriers' demonstrated good internal consistency (Cronbach's $\alpha = .86$). Reliability co-efficients were not reported for the subscales. The second section was a critical events scale (14 items)

referring to discrete events such as moving states, illness, divorce that might lead to ending of treatment. The critical events section was not used in this study as in the original development of the BTPS it did not significantly predict treatment drop out.

A shorter version of the BTPS was also developed (Colonna-Pydyn, Gjesfjeld, & Greeno, 2007) to improve the psychometric properties and make it more accessible for community populations. Exploratory factor analysis identified two factors and the 10 items with the highest loadings on each factor were selected to be included in the shorter scale. The two factor solution was confirmed ($\chi^2(168) = 193.4$, $p = 0.09$, CFI = .95, RMSEA = 0.03). Both factors: 'treatment expectations' (Cronbach's $\alpha = 0.9$) and 'external demands' were internally consistent ($\alpha = 0.8$). As little is known in SLT about barriers to attending and participating in intervention, the original BTPS was selected for use in this study to obtain the broadest perspective of parent experience.

Modifications were made to increase the relevance of the measure to NHS SLT (appendix 6.7). These included wording changes (table 6-4), the addition of one item and the deletion of four items:

Table 6-4 Wording changes: BTPS

Item no.	Original	Item no.	SLCN Version
3	My child was in other activities (<i>sports, music lessons</i>) that made it hard to come to a session.	3	My child was in other activities (<i>nursery, play group, drop in sessions</i>) that made it hard to come to a session.
8	I did not like my therapist.	8	I did not like my <i>child's</i> therapist.
25	I felt treatment did not <i>focus</i> on my life and problems.	25	I felt treatment did not <i>take into account</i> my life and problems.
29	My child's <i>behavior</i> seems to have improved, therefore, treatment no longer seems necessary.	29	My child's <i>communication skills</i> seem to have improved, therefore, treatment no longer seems necessary.
38	Getting <i>a baby-sitter</i> so I could come to sessions.	38	Getting <i>someone to look after my other child/ren</i> so I could come to sessions.
40	I had a disagreement with <i>my husband, boyfriend, or partner</i> about whether we should come to treatment at all.	40	I had a disagreement with <i>my partner</i> about whether we should come to treatment at all.
41	I was too tired <i>after work</i> to come to a session.	41	I was too tired to come to a session.

Added Item:

- 8a My child did not like their therapist.

Deleted Items:

9. I felt that treatment cost too much.
10. I was billed for the wrong amount.
37. The therapist did not call often enough.
35. My child was never home to do the assigned homework.

6.3.4 Child Characteristics:

SLTherapist led assessments (Chapter 8) will provide indices of child impairment severity. An additional measure, focused on functional communication, (how it affects activities and participation in the real world) was warranted as both the true and perceived impact of impairments can vary. A scale was required that would allow comparisons across all types of SLCN and be parent-rated. The IPQ-R and the FLQ also include parent perceptions of symptoms but are not standardised. The Focus on the Outcomes of Communication Under Six (FOCUS ©) (Thomas-Stonell, Oddson, Robertson, & Rosenbaum, 2009) is standardised and met these criteria.

The FOCUS was designed to measure change in children's functional communication (real world communication and interaction skills in different contexts) following SLT. It was developed in a SLT context with input from both parents and SLTherapists. It is aligned with the World Health Organisation's ICY-CY framework (WHO 2007) with a particular emphasis on the Activities (e.g. a "My child uses words to ask for things.") and Participation (e.g. "My child gets along with other children.") domains. The measure (total score) has demonstrated high internal consistency with both parents (Cronbach's $\alpha = 0.96$) and clinicians (Cronbach $\alpha = 0.94$). Test-retest reliability for parents was also high ($r > .95$) and inter-rater reliability for change, measured by the FOCUS total scores, was high (ICC = .70; 95% CI: .24-.91). Evidence of construct reliability was found through the identification of significant associations found with relevant domains of the Vineland Adaptive Behaviour Scales II (Washington et al., 2013). A single underlying construct was confirmed by factor analysis. The authors established a 'minimally clinical importance difference' (MCID) as a 16-point change in the FOCUS scores. This was based on a 95% agreement between parents' and SLTherapists' qualitative judgement that important functional changes had occurred at this level (Thomas-Stonell, Washington, Oddson, Robertson, & Rosenbaum, 2013).

There are two versions of the measure, one for parents (appendix 6.8) and one for clinicians; both contain the same 50 items. Parents are asked to rate their child on a seven point Likert scale providing a minimum score of fifty and a maximum score of three hundred and fifty. Higher scores indicate greater communicative competence. Five negatively worded items (24, 25, 29, 30, 32, 34) are reverse scored. In addition to a total score, a scoring profile is available; however, as it is only intended for clinical use in planning and setting goals it was not used in the present study.

Conclusion

This chapter reported on the scales and approaches that will be used to measure the dependant (attendance, adherence, child outcome) and independent variables within the domains of parent beliefs, parent experiences of treatment, their personal circumstances and child characteristics. Measures were confirmed with the exception of the following: for the measurement of adherence, two measures were potentially suitable. Within the *parent beliefs* domain, two domains of IPQ-R (Moss-Morris et al 2002) required adaptation for use within SLT and a measure of self-efficacy to follow SLT recommendations could not be identified from the literature, requiring it to be developed for this research. Within the domain of *treatment experience* two measures of satisfaction were identified as suitable. For these unconfirmed measures, a pilot study was considered appropriate to evaluate their appropriateness.

CHAPTER 7

Phase 2: Pilot study: identifying appropriate measures of adherence, satisfaction, self-efficacy and illness perceptions for use with parents of young children receiving SLT intervention.

Overview

This Chapter reports on the second empirical study of the thesis: a pilot study to confirm measures of adherence, satisfaction, self-efficacy and illness perceptions, for use in the main study. This pilot also included participant views on the acceptability and relevance of the measures. A further aim was to identify any issues with recruitment, including obtaining feedback from recruiting Speech and Language Therapist (SLTherapists).

Ethical and Research and Development approval was obtained for this study (REC reference: 11/LO/0031, Protocol number: CSA/11/001 amendment no. 1; R and D Reference RDLSou593).

7.1 Aims

1. To assess the appropriateness and acceptability of measures of adherence, satisfaction, self-efficacy and beliefs about SLCN (illness perceptions) to parents of children receiving SLT
2. To identify any challenges in the recruitment process when involving large numbers of SLTherapists over multiple sites.

7.2 Methodology

A pilot study was selected as it is an appropriate design for assessing the feasibility of processes, including development, delivery and return rates of questionnaires, and can identify any issues with participating centres such as recruitment and capacity, prior to a larger study (Thabane et al., 2010). Combined, these areas have the potential to improve quality and efficiency by identifying design deficiencies which can then be addressed prior to the implementation of the main study.

In keeping with good practice recommendations for pilot studies (Lancaster, Dodd, & Williamson, 2004), the measures that are included in this pilot study require evaluation for different reasons. Firstly, a reliable and valid measure of adherence is required as the main outcome measure in the main study and neither of the included measures have been used in SLT. Secondly, of the two satisfaction measures, the Client Satisfaction Questionnaire – 8 (CSQ-8) (Attkisson & Greenfield, 2004) is well validated and has been extensively used in a range of populations such as children’s neuropsychological services (Tracey & Kokotovic, 1989) and adult addiction (De Wilde & Hendriks, 2005) but not with parents of children with SLCN. The psychometric properties of the second satisfaction measure, derived from a SLT population, have not been reported (Grela & Illerbrun, 1998). Finally, a psychometric evaluation of the remaining two measures (self-efficacy and illness perceptions) would be appropriate as they have been developed and adapted specifically for use in this study. It is also important to assess the acceptability of these measures to parents of children with SLCN.

As a pilot study a sample size calculation was not undertaken; however, when revising existing or developing new scales in the context of a pilot study, a minimum sample size of thirty is

usually recommended to obtain a wide range of responses in examining the acceptability of these measures (Johanson & Brooks, 2010).

Recruitment and retention in studies is an ongoing challenge for researchers (Bower et al 2014). Minority group status, residing in an urban area, low levels of education, unemployed or low occupation status and low family income are considered barriers to research recruitment (Patel, Doku, & Tennakoon, 2003) and are relevant to the present thesis given their previously stated relationship with participation. In the previous qualitative study (Chapter 5), participants were recruited directly via the post, and independent of the SLT department and therapists. The recruitment rates were low and different across the two groups, twenty one percent for consistent attenders and six percent for inconsistent attenders. Consistent with the risk factors for non-participation in research, parents in the inconsistent group were more likely to be from a minority group with lower levels of education. The main study in this thesis requires a large and representative sample to ensure sufficient power to explore the effects of a large number of variables, and, as such, an effective approach to recruitment is required. Participants will be recruited at their first appointment in the main study. This will limit the timely availability of personal details thus the recruitment strategy will require SLTherapist involvement.

Recommendations for enhancing research recruitment include evaluating burdens and benefits (including incentives) to participants, communication and relationships. For staff involved in recruitment, how they are supported is also important, that is, through training, reminders and incentives (Bower et al., 2009; Patel et al., 2003). These factors were considered in the design of the recruitment strategy for this pilot. From the participant perspective, burden and the presentation of information were limited by the study requirements. To support participant understanding a brief summary sheet was attached to the questionnaire pack. Incentives were not considered due to the financial restrictions of a self-funded PhD. The established relationship between SLTherapists and participants was expected to enhance recruitment and facilitate communication about the study. All recruiting SLTherapists were known to the researcher, which provided a basis for enhancing relationships, motivation and interest in the research. Presentations about the research were delivered to the recruiters at a team level. Regular email contact was established, including reminders and positive feedback about progress. SLTherapists were also provided with a poster to serve as a prompt to ask potential participants (appendix 7.8). The burden on the

SLTherapist was kept to a minimum where possible, with the researcher taking responsibility for preparing and supplying the questionnaire packs.

7.3 Method

7.3.1 Participants

Participants were a consecutive sample of parents of young children (<5 years) with an accepted referral to an inner London SLT department and meeting inclusion/exclusion criteria listed below. The SLT department represents two boroughs (Lambeth and Southwark). Recruitment was over a nine month period beginning in July 2012 in one borough (Lambeth). Recruitment was initiated in October 2012 in the second borough (Southwark) following the integration of two local health services.

Inclusion criteria:

- Parents of children (<5 years) with an accepted SLT referral.
- A child was receiving SLT intervention (any type and duration).

Exclusion criteria:

- A child with a chronic or current medical illness
- A child who was subject to a child protection enquiry.
- A child who has been referred for additional intervention with the chief investigator.
- A parent who required the use of interpreting services.

Children who were ill or subject to a child protection enquiry were excluded as these experiences could have the potential to additionally influence parent beliefs and their involvement in SLT in a unique way. They were also excluded if they had received any intervention with the researcher in order to minimise both response bias, such as wanting to appear a certain way (social desirability), and the influence of the researchers prior knowledge during the telephone interview (Podsakoff, MacKenzie, Lee, & Podsakoff, 2003). Parents who required interpreters were excluded as all questionnaires were written in English and parents were required to complete them in their own time.

Qualified SLTherapists (N=34), working in the Early Years (EY) team within the SLT department, were collectively informed about this research. Therapists work in small teams representing

ten geographical clusters. They were provided with an information sheet detailing the study requirements, including their role (appendix 7.3). They were asked to give questionnaire packs to all eligible parents attending a routine SLT appointment. SLTherapists approached four hundred and fifty three parents of children on their caseload calculated on the basis of the number of packs returned at the end of the study. These parents, as part of their child's intervention, had been provided with recommendations for home practice and met inclusion/exclusion criteria. The response rate was six percent, permitting recruitment of twenty seven parents. Of the twenty seven parents who responded, three declined further contact; a further four were lost to follow up (attrition rate 26%). As such twenty parents completed the final questionnaire the M-ATIF (figure 7-1).

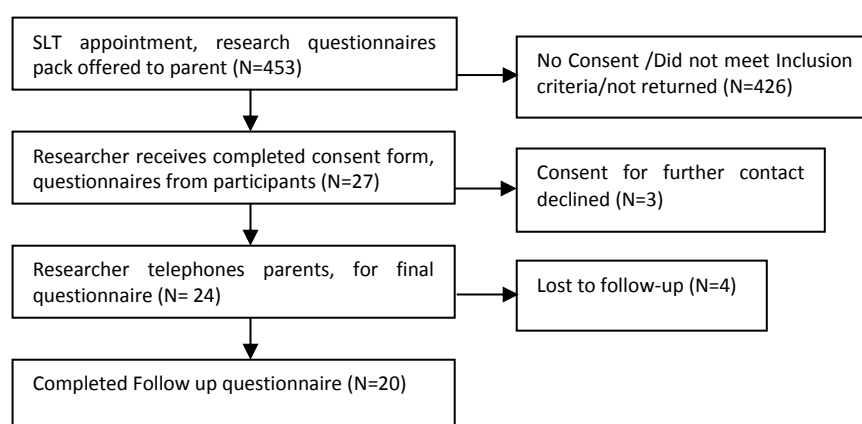


Figure 7-1 Recruitment Process

7.3.2 Procedure

The researcher prepared questionnaire packs (N=600) in batches providing SLTherapists with a ready supply. The pack contained an invitation letter, information sheet, consent form; copies of five questionnaires, including a feedback form for each and stamped addressed envelopes (appendices 7.4-7.16). The participating parents independently completed all measures except the MATIF (Dreyer, et al., 2010). On receipt of the consent form and completed questionnaires the researcher obtained copies of the SLTherapist's recommendations given to the parent. The researcher then telephoned parents to complete the MATIF. Coding was applied to all measures, separating participant identifying information from the data to ensure confidentiality was maintained.

Both qualitative and quantitative parent feedback was used to inform decisions on the acceptability of the measures including exploring any patterns in missing data. Measures were

also considered acceptable if they demonstrated sufficient variance as assessed by descriptive statistics, and demonstrated acceptable internal reliability using Cronbach's alpha (minimum of 0.7) (Nunnally et al 1967).

The recruitment process was monitored throughout the study. Feedback on this process was sought from the recruiting SLTherapists using a brief on-line evaluation questionnaire.

7.3.3 Measures

Adherence and satisfaction measures were identified from a review of the literature taking into account the populations reported, the potential relevance to SLCN and SLT, and, where available, the psychometric properties of the measures (see Chapter 6). Each measure (appendices 7.11 -7.16) included a parent feedback section designed to obtain information on the acceptability of the measures (appendix 7.10).

7.3.3.1. Adherence:

a) The Homework Rating Scale II (HRS II) (Kazantzis et al., 2003)

This measure was originally developed to measure various aspects related to the quantity and quality of homework adherence in the context of psychological treatment with adults. Only the client version was used, although both client and therapist versions are available. It is a 12-item self-report measure; factors include difficulties experienced in following the recommendation, any barriers, understanding and mastery of a task and enjoyment of an activity. Participants were asked to rate their agreement with a statement, for example, "I was able to do the activity", on a 5-point scale where 0 was 'not at all' and 4, 'completely'. The measure is comprised of three internally consistent factors: (a) Beliefs (Cronbach's $\alpha=.75$) (with items: comprehension, rationale, collaboration, specificity and match with therapy goals), (b) Consequences (pleasure, mastery and progress) (Cronbach's $\alpha=.80$), (c) Engagement (quantity, quality, difficulty and obstacles) (Cronbach's $\alpha=.81$). The total scale has also demonstrated good internal consistency (Cronbach's alpha = .89) (McDonald & Morgan, 2013). Preliminary validity for the components of the HRS II has been confirmed (Deane, Mercer, Talyarkhan, Lambert, & Pickard, 2012). Items within each factor are totalled with higher scores representing positive performance. The range of scores for each subscale are Beliefs: 0 -25, Consequences: 0 -15 and Engagement 0 - 20.

In this study minor modifications were made to the wording of the measure, including changing the word 'people' to 'parent' and adding 'with my child' so that 'I was able to do the activity' became 'I was able to do the activity with my child'.

b) The Modified- Adherence Telephone Interview Form (MATIF) (Dreyer et al 2010)

The Adherence Telephone Interview Form (ATIF) was originally developed to evaluate parental adherence to recommendations for children referred for psychological intervention (MacNaughton & Rodrigue, 2001). In this version an interviewer begins with an explanation of the interview and then asks parents specific questions about each recommendation in turn. Parents are then asked if they completed the recommendation or not and were classified as adherent if they had completed or initiated the recommendation, or otherwise non-adherent. An adherence score was calculated by dividing the number of recommendations completed/initiated by the total number of recommendations. Parents were also asked "Did anything make the recommendation difficult to complete?" and asked to provide a description of the barrier if appropriate. Barriers were categorised by interviewers into financial problems, competing demands (time or scheduling), access problems or negative attitudes or beliefs. Recommendations were coded according to four different types: psychological services, school-based recommendations, professional: non-psychological and active self-help. Good inter-rater reliability was reported (Barriers: kappa coefficient = 0.87, Recommendations: kappa = 0.74) (MacNaughton & Rodrigue, 2001). This version was also used with parents of adolescents coping with pain (Claar & Simons, 2011; Simons, Logan, Chastain, & Cerullo, 2010), although in both studies a definition of 'partially adherent' was added for parents who discontinued a recommendation after starting, therefore a parent who was fully adherent was given a score of 1.0, partially adherent 0.5 and non-adherent 0.

Dreyer et al (2010) modified this version for parents of children with ADHD. Their adaptations included introducing a 5-point scale in response to the question 'did you complete this recommendation' rather than the original dichotomous scale. Adherence was calculated in two ways, using the original dichotomous classification and a calculation using the 5-point scale; higher ratings indicated a higher level of adherence. Adherence was higher in dichotomous ratings. New to this version was an importance rating for of each recommendation, also on a five point scale (1= not important, 5=extremely important). In

contrast with the open-ended question asked in the original version parents were also provided with a list of barriers that may have interfered with their ability to complete the recommendation and asked to select those that applied to their experience. Barriers included: didn't think it would help, no longer a problem, resources not available in my community, transportation, insurance, time, and forgot to do it. An open-ended question was added for participants to comment on any other type of barrier. Further changes included parent and teacher ratings child's behaviour-change and to rate the level of improvement (or worsening if appropriate). Ratings for all behaviour-change questions were on a 5-point scale (1= a little better/worse, 3 = better/worse, 5= much better/worse). The final addition was an open ended question about what might have helped parents follow the recommendations better. The psychometric properties of this version were not reported.

In this pilot study the Dreyer et al (2010) version was adopted. Minor changes to the wording in the introduction were made reflecting the difference in services and type of practitioner. One of the barrier items was dropped (insurance) as it is not applicable to a NHS SLT service which is free at the point of use. The 5-point adherence scale was selected as potentially providing greater sensitivity. Following the same procedure as the authors, an overall score was calculated by converting the 1-5 scale to 0-4 (zero now representing a non-completed recommendation). Total scores for all recommendations were then averaged, and multiplied by one hundred to provide degree of adherence. The classification of type of recommendation was adapted for SLT:

A: Active self-help: Parent to initiate or engage in some form of active self-help strategy.

B: Professional: non-psychological: Consult with a professional other than a SLT.

C: School-based: Involving the school, tutoring, or school academic-related programs.

D: SLT services: Any type of SLT or another SLT evaluation.

7.3.3.2 Parent Satisfaction:

a) Client Satisfaction Questionnaire (CSQ-8; Attkisson & Greenfield, 2004)

This 8-item satisfaction measure has been extensively used in medical and mental health settings and also in research. Items are scored on a 4-point scale and include statements such as "In an overall sense, how satisfied are you with the service you have received?" Scores range from 8 to 32; a higher score indicates a greater satisfaction with the service being evaluated. It was selected for use in this study due to its applicability for use in a variety of settings and its excellent reliability, internal consistency and acceptability to clients and services (Attkisson & Greenfield, 1996, 2004; Hodges et al., 2003). No published record of its use in SLT was located. The UK English version of the CSQ-8 which uses British English spelling conventions and replaces the word "service" with the word "program" was purchased for use in this study. No changes were made to any item or item-response as they are not permitted under the copyright terms. Consent for use was obtained from the first author C. Attkisson, along with the purchase of fifty questionnaires.

b) Consumer Satisfaction with SLT: parent questionnaire (CSPQ) (Grela & Illerbrun 1998)

This 22-item questionnaire was developed by two SLTherapists and three parents with direct experience of SLT services (Grela & Illerbrun 1998). Items were categorised into seven themes: referral process, service convenience, assessment process, parent intervention, parent support, intervention format, and parent satisfaction. Parents were asked to rate their agreement with each statement using a 5-point Likert scale (1 = Strongly Disagree, 3 = No Opinion, 5 = Strongly Agree) and a total score calculated (maximum 110), higher scores reflected greater satisfaction with the service. A psychometric evaluation of the measure was not undertaken in the original study and the questionnaire remains un-validated. This measure was selected for its relevance and direct applicability to the service model used within SLT.

7.3.3.3 Self-efficacy:

Self-efficacy to follow SLT recommendations (SE-SLTR)

This measure was developed for this research using a guide for developing self-efficacy scales (Bandura, 2006). Self-efficacy is domain specific in that a person's beliefs in their own

capabilities are specific to certain areas of functioning rather than being a global trait. The SE-SLTR was developed to examine a parent's judgement of their ability to carry out the recommendations made by their child's SLTherapist when faced with certain additional demands that would challenge their performance in the prescribed task, such as when they are tired or if their child is unwell. Potential demands were derived directly from parents of children with SLCN (Chapter 5), and supplemented with relevant barriers from a self-efficacy scale in physical exercise (Schwarzer, 1993). Nine barriers were listed and presented in the following format: I am confident that I can carry out the home-based activities with my child, that were recommended by the speech & language therapist even if... e.g. a) I am tired or h) I have lots of other things to do. The scale was written using plain English and included phrases used by parents in the qualitative study to minimise scale or item ambiguity (Podsakoff et al., 2003). Parents rated their degree of confidence on a 7-point scale with 1 being 'not at all confident' and 7 being 'very confident'. A 7-point scale, as used by Schwarzer (1993), was selected over a 5-point scale as a means of increasing sensitivity. A single self-efficacy score was calculated by totalling all scores, with a potential range of 9 – 63; higher scores indicate higher self-efficacy. The final version was judged to demonstrate face validity by two specialist SLTherapists.

7.3.3.4 Illness Perceptions:

Revised Illness Perceptions Questionnaire (IPQ-R) (Moss-Morris, et al., 2002) adapted for SLCN (IPQR-SLCN)

The IPQ-R (Moss-Morris, et al., 2002) assesses an individual's cognitive representations of their own illness. The questionnaire is divided into three sections, the first of which is 'identity', which is concerned with a person's ideas about the symptoms of their illness and the relationship with the illness label. The identity scale includes a list of twelve commonly experienced symptoms in chronic illness which were originally identified from other symptom lists (Weinman et al., 1996) with two further symptoms added in the revision of the IPQ (Moss-Morris, et al., 2002). Patients are asked to report if they have experienced each symptom (yes/no) and identify if it is related to their illness (yes/no).

The second section examines illness perceptions across seven domains: i) *timeline acute/chronic* (the extent to which the patient perceives their condition as short or long lasting), ii) *timeline cyclical* (the extent to which the patient perceives their illness to be cyclical in nature), iii) *consequences* (the extent to which the patient perceives their condition to be

serious and have significant impact on functioning), iv) *personal control* (the degree of control a patient believes they have over their illness), v) *treatment control* (the degree of control the patient perceives the treatment has over their illness), vi) *illness coherence* (the extent to which a patient believes they have a coherent understanding of their illness), and vii) *emotional representations* (the extent to which a patient evaluates their illness to have an impact on their emotional state). This section includes thirty two statements related to these domains and patients are required to rate their agreement with each on a 5-point Likert scale.

The final section reflects an individual's views on the potential cause(s) of their illness and includes a list of eighteen potential causes derived from studies of specific illnesses using the IPQ, rated using a 5-point Likert scale. In addition, the patient is asked to state the three most important causes for them. The IPQ-R is considered to be acceptable psychometrically demonstrating good internal and test-retest reliability (Hagger & Orbell, 2005; Moss-Morris et al., 2002). The authors of the IPQ (Weinman et al., 1996) and the IPQ-R (Moss-Morris et al., 2002) actively encourage the adaptation of these measures for use in different clinical populations and for different disease types in recognition of the unique and individual characteristics of different populations and illnesses.

For the purpose of this pilot study a number of adaptations were made to the IPQ-R based on the findings from a previous qualitative study (Chapter 5) to produce the IPQR-SLCN. In the qualitative study, parents provided their views on the symptoms that their child presented with (appendix 7.1) and their view of causes of their child's SLCN (appendix 7.2). No changes were made to the response scales.

General changes:

Modifications to the wording were made such as replacing 'your illness' with 'your child's communication problem' or 'your child's problem'; 'your symptoms' were replaced with 'your child's difficulties'. Some definitions were included to aid in understanding the test requirements. In the identity section definitions supported understanding of the difference between 'problem' and 'difficulty'. In the illness perception section: views about your child's problem the use of the word treatment was defined as referring to SLT intervention.

Identity Scale changes:

In a previous qualitative study (see Chapter 5) parents described their child's symptoms and these were classified by the researcher into the domains of expressive language, receptive language, speech, social communication, gesture and dysfluency. Additional symptoms were categorised into behaviour and learning (see Appendix 12). These formed the basis for the list of reported symptoms. Parent support websites for SLCN (ICAN: www.ican.org.uk) and also autism (National Autistic Society: www.autism.org.uk) were also examined to identify common language used to describe symptoms of communication disorders. The final list, including thirty items, was ratified by two senior SLTherapists including the researcher.

'Illness Perception' Scale changes:

Additional items were added to the Consequences and Personal Control domains to take account of the potential contributions of the child, parent and SLTherapist rather than just the child. For example item IP7c "My child's problem has major consequences on **their** life" and IP7p "My child's problem has major consequences on **my** life" and IP13c "What **my child** does can determine whether their problem gets better or worse", IP13p "What **I** do can determine whether my child's problem gets better or worse" and IP13s "What the **speech & language therapist** does can determine whether my child's problem gets better or worse". The specific belief 'fear for the future' replaced "my illness makes me feel afraid" as it emerged as a common theme in the qualitative study (Chapter 5). The final scale included 50 items with the original numbering retained. Where additional questions were added as described above, the letters 'c' (child), 'p' (parent) and 's' (SLTherapist) were included to differentiate between contributors.

Cause Scale

All causal attributions mentioned by parents in the qualitative study (Chapter 5) were included and supplemented by retaining some of the original IPQ-R items and the addition of one item: "Because it is God's will" (see Appendix 13). Although parents did not refer to religion in the qualitative study, personal experience of working with families suggested that its inclusion was appropriate when aiming to be over-inclusive when piloting a measure. The final scale included 28 items.

7.3.4 Analysis Plan

1. Descriptive: the means, standard deviations and distribution of scores will be examined to allow a comparison with published data, where available, and ensure sufficient variance i.e. to ensure that there are no floor/ceiling effects or skewed distribution. A distribution will be accepted as normal if the z-score of skewness falls between -1.96 and 1.96 (Field 2005).
2. The index of internal reliability used will be Cronbach's Alpha providing a measure of the internal consistency of each test with alpha's greater than 0.7 (Nunnally et al 1967).
3. Where more than one measure addresses a particular construct i.e. adherence/satisfaction, correlations between the measures will be examined to identify the amount of overlap between measures and to assist in the final choice of measures for the main study.
4. Both Parent feedback and feedback from SL therapists involved in recruitment will be analysed in two ways: a thematic analysis of qualitative data analysis and the reporting of percentages response rates.

7.4 Results

7.4.1 Participants

Twenty seven parents returned questionnaires. Twenty six completed the first five questionnaires in full (HRS II, CSQ 8, CSPQ, SE-SLTR, IPQR-SLT), one parent only fully completed one (SE-SLTR) and partially completed four of these questionnaires (excluded from analyses). This participant was also lost to follow up along with six other parents (attrition rate 26%) leaving twenty parents who completed the final questionnaire: the M-ATIF.

Participants were parents of children with an average age of 46 months; information was unavailable for three participants as they declined further contact from the researcher. Only one father participated; no further information on the parents was collected. Child data included a description of SLCN, other diagnoses, ethnicity, type of intervention received, number of SLT sessions offered, percentage attendance and length of time known to SLT (as at April 2013) and where appropriate, discharge reason (Table 7-1) .

The children presented with a range of SLCN. Twelve children (44.4%) presented with SLCN as their only difficulty, eleven children (40.7%) had additional diagnoses and data was not available for four children (14.8%). Families came from a range of ethnic backgrounds with a third (33.3%) describing their child as being white British. The majority (66.7%) were actively involved with SLT and of those discharged from SLT; no child was discharged for non-attendance. Children received a range of SLT interventions and high levels of attendance was observed with only three parents having an attendance rate of less than 80%. The number of SLT sessions offered to a child and their parent averaged 18-19 sessions but varied widely (7-45). Children had been known to the SLT service from between seven and thirty two months, (\bar{X} =20.6). One participant was excluded from these latter two calculations due to the exceptionally high number of sessions offered (n=286); this child was being seen by the SLT service primarily for eating and drinking difficulties since birth.

Table 7-1 Sample Characteristics: Children & SLT interventions

Variable	Total	
Age of child at Recruitment (n=24)	Mean 46 months (SD 7 months Range 27 – 56 months)	
SLCN Description by SLT		
(NB multiple descriptions given per child)	expressive	5 (20.8%)
	receptive	1 (4.2%)
	mixed expressive/receptive	13 (54.2%)
	social communication	5 (20.8%)
	attention & listening	10 (41.7%)
	speech	13 (54.2%)
	stammer	2 (8.3%)
	Feeding	1 (4.2%)
Medical Diagnosis	none	12 (50%)
(NB multiple descriptions given per Child)	global developmental delay	3 (12.5%)
	Autism	3 (12.5%)
	Hearing impairment (conductive/sensory)	2 (8.3%)
	Developmental Co-ordination Disorder	2 (8.3%)
	Cleft Palate	1 (4.2%)
	Not known	4 (16.7%)
	Other congenital disorder	2 (8.3%)
Ethnicity (N=27)	White British	8 (33.3%)
	White -any other background	2 (8.3%)
	White - other European	2 (8.3%)
	White-all republics USSR	1 (4.2%)
	Mixed - White & Black African	2 (8.3%)
	Mixed - White & Black Caribbean	1 (4.2%)
	Mixed-any other mixed background	1 (4.2%)
	Black or Black British – British	1 (4.2%)
	black or black British Caribbean	1 (4.2%)
	Black or Black British - Any other background	1 (4.2%)
	Asian or Asian British – Pakistani	1 (4.2%)
	Other Ethnic Groups – Arab	1 (4.2%)
	not known	5 (20.8%)
Discharge Reason (N=27)	n/a referral active	16 (66.7%)
	non-attendance	0
	Treatment no longer required	4 (16.7%)
	Due to school age service limitations	3 (12.5%)
	Attends out of borough school	1 (4.2%)
	Not known	3 (12.5%)
Type of intervention offered	Language group	11 (45.8%)
(NB multiple offered per child)	SLI group	5 (20.8%)
	ITTT	1 (4.2%)
	PCI	7 (29.2%)
	Palin PCI	1 (4.2%)
	MTW	1 (4.2%)
	Lidcombe	1 (4.2%)
	Speech	6 (25%)
	PECS	2 (8.3%)
	Feeding intervention	1 (4.2%)
Percentage Attendance (n = 24)	Mean 97 (SD 14.7 Range 43-100%)	
No. Of SLT Sessions offered (n =23*)	Mean 19.5 sessions (SD 10.8 Range 7 - 45 sessions)	
Length of Time known to SLT (n =23*)	Mean 20.6 months (SD 7.2, Range 7 – 32 months)	

KEY: SLI: Specific Language Impairment; ITTT: It Takes Two to Talk Group format with parents; PCI: Parent Child Interaction; Palin PCI Parent Child Interaction in stammering, MTW: More Than Words Programme Group format with parents; Lidcombe: stammering intervention.

* Outlier excluded

7.4.2 Questionnaires evaluation

The descriptive statistics, measures of internal consistency (summarised in table 7-2) and where appropriate, comparative statistics for the measures, were calculated using correlational analysis. Given the small sample size of twenty seven this would provide sufficient power to predict correlations greater than $r=.52$, $p=.05$ (two-tailed), $\beta=.02$ (type 2 errors). Participant feedback was considered to explore the acceptability of the measures.

Table 7-2 Summary of measures: descriptive statistics, internal consistency

Measure	N	Missing	Mean (SD)	Range	ZSkew	Cronbach's
HRS II II (Total)	26	1	44.9 (5.32)	29-56	-1.42*	.74
Beliefs (5 items)			20.9 (2.86)	13-25	-2.27 [Ⓢ]	.39
Consequences (3 items)			12.2 (2.15)	8-15	-0.82*	.61
Engagement (4 items)			12 (1.60)	8-16	-1.38*	.45
MATIF Adherence (1 item)	20	7	79.1 (14.7)	46-9-	-0.85*	n/a
CSQ 8	26	1	28.3 (4.14)	18-32	-2.56 [Ⓢ]	.93
CSPQ	26	1	92 (9.6)	74-	-0.99*	.91
SE-SLTR	27	0	44.7 (11.3)	28-63	1.13*	.90
IPQR-SLCN	26	1				
Identity (total)	26	1	9.07 (7.43)	0-28	2.69 [Ⓢ]	n/a
Symptoms not related to SLCN (total)	26	1	2.54 (2.52)	0-8	2.07 [Ⓢ]	n/a
IPQR-SLCN Views						
Timeline	26	1	14.4 (6.58)	6-29	1.59*	.87
Consequences Total	26	1	24.9 (8.64)	12-42	1.31*	.91
Consequences Child	26	1	9.04 (3.21)	3-15	0.64*	.76
Consequences parent	26	1	8.54 (2.98)	3-14	1.50*	.73
Personal Control Total	26	1	54.4 (10.1)	35-81	0.93*	.76
Control Child	26	1	19.9 (4.54)	11-26	-1.47*	.65
Control Parent	26	1	23.7 (6.32)	16-50	6.54 [Ⓢ]	.54
Control SLT	26	1	10.9 (2.43)	4-15	-1.41*	.34
Treatment Control	26	1	19.7 (3.71)	10-25	-2.13 [Ⓢ]	.65
Illness Coherence	26	1	20.3 (4.49)	8-29	-1.20*	.92
Timeline Cyclical	26	1	8.77 (4.50)	0-20	0.92*	.91
Emotional representations	26	1	17.1 (5.87)	7-29	0.58*	.89
IPQR SLCN Causes endorsed total	26	1	2.76 (2.49)	0-10	3.50 [Ⓢ]	

*distribution assessed as normal (Z-Skew <1.96) Field 2009

7.4.2.1 Adherence measures:

1. The Homework Rating Scale II (HRS II) (Kazantzis et al., 2003)

With the exception of the *Beliefs* subscale (Zskew -2.21), all subscales and total score were normally distributed (Zskew -0.42--1.42). The '*Beliefs*' subscale was negatively skewed, indicating higher beliefs in SLT treatment. With the exception of the participant who only completed one measure there was no missing data.

The overall scale demonstrated acceptable reliability ($\alpha = .74$); this is lower than reported previously ($\alpha = .87, .89$) (Deane et al., 2012). The internal consistency for the Beliefs, Consequences and Engagement subscales was either poor or unacceptable ($\alpha = 0.39, 0.61, 0.45$ respectively). Although previous research has provided preliminary confirmation of the three component's (Deane et al., 2012), the results here suggests that this three factor solution may not hold true in this SLT population. A confirmatory factor analysis was not undertaken however, due to the low numbers of participants.

Parent feedback: Parent ratings of ease of understanding and completion were high and all twenty six parents completed it in full. Comments from two parents raised the difficulty in answering the questions with the absence of a specific therapy activity.

"It is difficult to answer as we were given lots and lots of different activities, some easier, more relevant than others, some things need equipment or some are suggestions, some take time, some don't so it's different to generalise."

"however, the questions were difficult to assess as they did not refer to particular homework"

2. The Modified Adherence Telephone Interview Form (MATIF) (Dreyer et al 2010)

In contrast to the other scales, the MATIF was administered by the researcher over the telephone. It included a single item representing adherence to a recommendation. Participant responses to this item were normally distributed (Zskew = -0.85) and the degree of adherence ranged from 46.9 to 100 indicating that this measure was sensitive to capturing a range of adherence measurements. The mean rate of adherence was higher in the present study (\bar{X}

=79.1) as compared to the original authors (\bar{X} =67.5) (Dreyer et al 2010); however, this may reflect different services and populations. There was no missing data.

All types barriers were endorsed at least once when responding to a recommendation, indicating that they were relevant. Participants were also provided with an opportunity to provide any other barrier not previously specified with an open ended question: *“Was there any other reason that I didn’t mention that made it more difficult for you to follow this recommendation?”* Not all parents commented and the number of comments reduced for each successive recommendation. Comments were typically clarifications of previous answers; no new barriers were identified.

e.g. for parents endorsing ‘my child didn’t want to do it’:

“very hit and miss, it depends on her mood at the time.”

“she do sometimes play with other things, sometimes doesn't want to do it”

Parent feedback: Some parents found the wording of the introduction to the barriers section difficult to understand which required the researcher to modify this section during the pilot.

The last section was amended to:

(Read each option to parent, **add “*did that interfere with following the recommendation?*”** and circle response)

Some parents found the Barriers section repetitive.

“yes there was a variety of questions but this questionnaire [MATIF] was very repetitive, even though I understand the reason, it made me lose enthusiasm.”

But others were unaffected:

“don’t have a problem with it the questions were relevant”

One parent used this opportunity to reflect on her overall experience of completing the questionnaires:

“some of the questions made me think. There was one about 'your fault' it made me think could I have done something else? It was good, it was the first time I actually thought about some of these things, they wake you up a little.”

Adherence Measure Comparisons: The scores of the single adherence item in the MATIF and one item in the HRS II engagement factor: 'quantity', were converted to Z scores to allow comparisons to be made; once transformed both were normally distributed. A sample size of twenty was sufficient to detect a correlation of $r=.59$ $p = .05$ (two-tailed). Measures were completed at different time points. The MATIF adherence score was significantly correlated with HRS II quantity, $r = .67$, p (2 tailed) = .001. The HRS II represented a generalised measure of adherence as opposed to the MATIF which was generated from specific recommendations. In addition, a dependent T-test confirmed that on average there was no significant difference between the measures ($t(19) = 0.70$, p (2-tailed) = .50), indicating that one may not be superior to the other from this perspective.

Parent feedback: Parents rated how easy the questionnaires were to understand and rate, how relevant they were and, for the HRS II only, if they added new information as compared to other measures. This last question was not asked following the MATIF as it was completed at a different time point to the others. In the HRS II parents commented how long it took to complete; in the MATIF the researcher timed the interview. A summary is provided in Table 7-3.

Table 7-3 Parent evaluations of the HRS II & MATIF

Question	HRS II	MATIF
Easy to understand (% agree/strongly agree)	92.6	95
Easy to rate (% agree/strongly agree)	81.4	90
Relevant (% yes)	88.9	94.7
Adds new information (% yes)	88.9	n/a
Time to complete (mins)	M=5 (mode n=12)	M=21.8

Both measures were overall understandable, easy to complete and relevant. Parent ratings were higher for the MATIF, particularly in ease of rating and relevancy. The ease of rating may be related to the involvement of the researcher in the administration of this questionnaire. Rating their child's specific recommendations may have positively influenced the rate of relevancy in the MATIF. The MATIF took longer to complete, although no parent commented on this.

A decision was made to select the MATIF over the HRS II. The HRS II is intended as a multi-factorial measure of adherence, however, there is an indication that the factors may not hold

true in this population. One item from the HRS II was used as a comparable index of adherence to the MATIF, both were highly correlated and suggesting convergent reliability. However, the main criticism of the HRS II was its lack of specificity in relation to a child's SLT recommendations. The MATIF, although longer to complete, also included a specific barriers section which is unique to this measure.

7.4.2.2 Satisfaction measures:

1. Client Satisfaction Questionnaire (CSQ-8; (Attkisson & Greenfield, 2004)

This measure showed excellent internal consistency ($r = .93$) commensurate with previously published results (Attkisson & Greenfield, 1994, 2004). Results were negatively skewed ($Z_{skew} = -2.56$) indicating that parents in this sample had a high level of satisfaction with SLT. Missing data was minimal with only a single item missed and only one occurrence. The item was 'to what extent has our program met your needs?'; the reason for the omission is unknown.

Parent Feedback: Only one parent responded qualitatively to this questionnaire and her comment related to her experience of SLT rather than feedback on the questionnaire:

"It was very bitty at the start because we had to keep changing therapist, but since we have had the same person my child has made much more progress."

2. Consumer Satisfaction with SLT: parent questionnaire (CSPQ) (Grela & Illerbrun 1998)

A single satisfaction score was calculated by totalling all scores and the data was normally distributed ($Z_{skew} = -0.99$). Most scores were high (range = 74-110) compared to the potential range (22-110) indicating, as with the CSQ8, that most parents were satisfied with SLT services. This scale demonstrated excellent reliability ($\alpha = .85$). Reliability could be further improved with the deletion of two questions (17, 18) ($r = .91$) leaving a twenty item measure. Their removal was not considered to be detrimental to the measurement of satisfaction as they may not reflect parental experience of the SLT department in this study. Missing data was minimal with one participant omitting to respond to one statement (15. SLT appointments were suitably spaced).

Parents did not provide any qualitative feedback on this questionnaire.

Satisfaction Measures: Comparisons: The correlation between the total scores from both measures was considered. A sample size of twenty six was sufficient to detect a correlation of $r=.53$ $p=.05$ (two-tailed). The CSQ8 total score was significantly correlated with the CSPQ total score, $r_s(25) = .81$, $p(2 \text{ tailed}) = .01$, providing evidence of convergent reliability with both scales measuring theoretically similar concepts.

Parent Feedback: Both measures were overall understandable, easy to complete and relevant. Parent ratings of ease of understanding and adds new information were higher for the CSPQ, ease of rating was equivalent but relevancy was higher in the CSQ8. The approximate times to complete the scales were also similar (table 7-4).

Table 7-4 Parent evaluations of CSQ8 & CSPQ

question	CSQ8 (% agree/strongly agree)	CSPQ (% agree/strongly agree)
Easy to understand	85.1	88.9
Easy to Rate	85.1	85.2
Relevant	92.6	88.9
Adds new information	85.2	88.9
Time to complete (mode)	5 (n=12)	5 (n=14)

Evidence for the superiority of one measure over the other was scant; however, the decision was made to use the CSPQ over the CSQ8 as this measure was designed specifically for SLT and may be of future benefit to the SLT profession.

7.4.2.3 Self-efficacy:

Self-efficacy to follow SLT recommendations (SE-SLTR)

Developed for this study, a single self-efficacy score was calculated by totalling all scores, with potential range of 9–63. The data were normally distributed (Zskew 1.13) with an actual range of 28-63, higher scores indicate higher self-efficacy. The measure was reliable with excellent internal consistency ($\alpha = .90$). There were no missing data.

Parent feedback: The majority of parents (96.3%) agreed or strongly agreed that this questionnaire was easy to understand, easy to rate (85.1%), relevant (96.3%) and added different and important information (92.6%). The majority (80%) thought that the questionnaire took less than five minutes to complete, some (15%) said 10 minutes and one (5%) stated that it took her thirty minutes to complete. No parent provided any qualitative comments.

This questionnaire was judged to be reliable, quick to complete, acceptable by parents and was included in the main study.

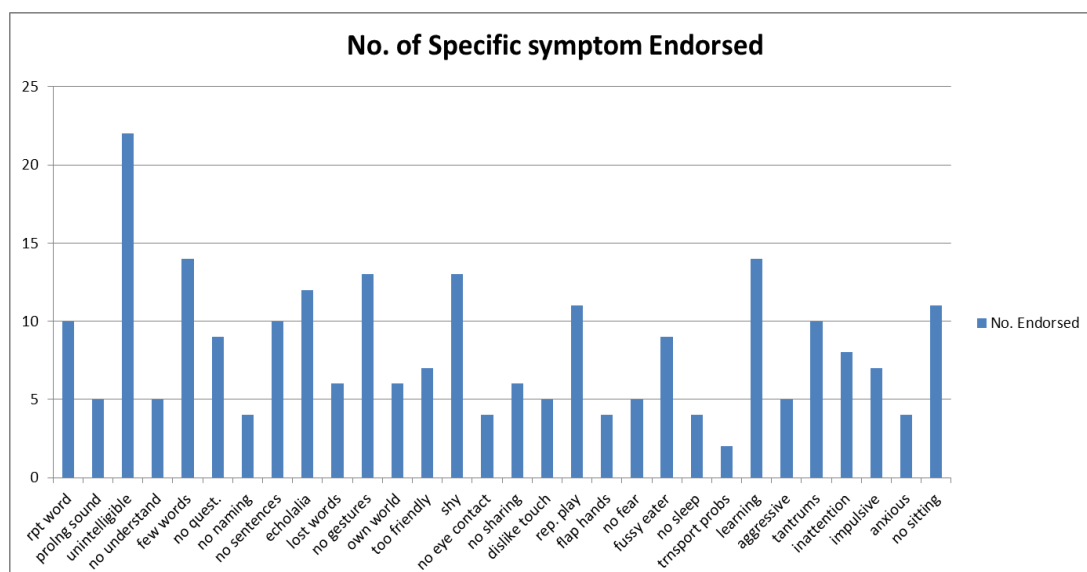
7.4.2.4 Illness Perceptions:

Revised Illness Perceptions Questionnaire (Moss-Morris, et al., 2002) adapted for SLCN (IPQR-SLCN)

Identity scale:

The number of symptoms identified by parents ranged from 1 to 28 with an average of nine symptoms, although the data were positively skewed ($Z\text{-skew} = 2.69$). Of these symptoms, parents considered that on average 2-3 symptoms were unrelated to their child's SLCN. All items were endorsed by at least two parents suggesting that the range of symptoms are representative of SLCN in this group of parents and confirming face validity (table 7-5). The number of endorsements per item ranged from two to twenty two. The most highly endorsed statement was Item 3: 'doesn't speak clearly' and the lowest was Item 23: difficulties taking him/her on public transport'. There were no missing data and no qualitative feedback by parents on this section.

Table 7-5 Endorsement (y-axis) of symptoms (x-axis) (ratings >4)



Views about problem:

The range of responses on each subscale was generally broad and all, except *control -parent* were normally distributed indicating that variations in beliefs were captured. Missing items were few and from one participant. This participant typically missed out those items that were reverse scored suggesting that these may have been harder to understand. The inclusion of reverse scored items is however, important for reducing bias (Podsakoff et al., 2003).

Internal consistency of six of the seven domains was acceptable ($\alpha = .76$ to $.92$) which is comparable to published data with alpha's between $.79$ and $.89$ reported in the initial validation of the IPQR (Moss-Morris et al., 2002). The *Treatment control* domain was minimally acceptable ($\alpha = .65$). The subscales of the *Consequences* domain were also reliable ($\alpha = .73$, $.76$). Within the *Personal Control* subscales, internal consistency was poor, except for *child-control*, which was minimally acceptable ($\alpha = .65$). Although *Parent-control* was poor ($\alpha = .46$), it was retained as lack of parental control featured in the qualitative study (Chapter 5). The *SLTherapist-control* subscale was not acceptable with an alpha of 0.34 and was removed from the final measure.

Parent feedback: One parent provided qualitative feedback on this section and who welcomed the focus on the child and family at home.

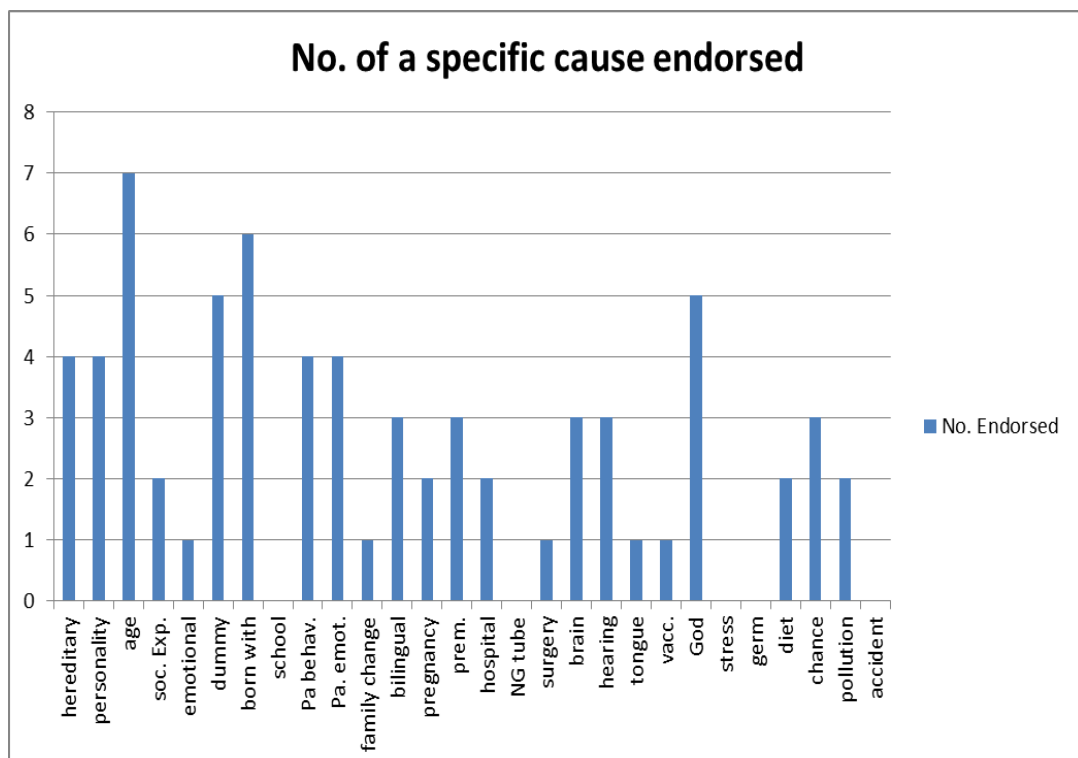
"questions were based on child at home and family rather than just the treatment by the speech therapist" [said in a positive tone]

Cause scale:

The items on the cause scale were considered representative of parent beliefs with all but four items being endorsed by at least one parent (table 7-6). For these four items ‘Started school too early/ because of a tube my child had in his/her throat’/stress or worry/germ or virus’, the majority of participants (95%) disagreed with the statements. However, as at least one participant in all items expressed uncertainty, through neither agreeing nor disagreeing, these items were not excluded. The frequency of endorsement for some items was low (5%) but given the explorative nature of this PhD it was important to be over inclusive.

Parents were also asked to record the three most important causes for them, twenty three parents completed this section and the majority of these responses matched their quantitative responses, for example one parent strongly agreed with the statement caused by hearing loss, endorsed no other causes and wrote *“Bilateral Moderate Sensory-neural hearing loss”*. Of some interest are the ratings by the two parents who indicated that they didn’t know the cause with the comments *“No idea”* and *“I don’t think anyone knows why my child’s problem developed - none of the above.”* The first parent strongly disagreed with all statements, the second endorsed ‘my child’s age’ and endorsed neither agree/disagree for the ‘chance or bad luck’. This may indicate that parents may use the scales differently to represent their views.

Table 7-6 No. endorsements (y-axis) per cause (x-axis) endorsed (ratings >4)



Parent feedback: This section received the most comments from parents and included statements qualifying their answers:

“some were n/a as they were not causes or explanations for my child's problems”

“Causes for me - this is irrelevant”

Another made a formatting suggestion:

“Add title to second page of IPQ views”

With the remaining requesting additions:

“what about are you happy with the SLT results?”

“add thumb sucking”

IPQR-SLT Overall Parent feedback: Feedback was received from all those who completed this questionnaire. In comparison to the other questionnaires overall ratings were lower. The majority considered it easy to understand (63%), although many were unsure (33.3%) and one participant strongly disagreed (3.7%). Most considered it easy to rate (70.4%), but some were uncertain (18.5%) and three did not agree (11.1%). The majority of parents (85.2%) believed that the measure added new information and was relevant to their experience of SLT (77.8).

Completion times ranged between 4-60 minutes, with the most frequent responses being between ten and fifteen minutes (n=15). Completing this measure in less than ten minutes seems implausible given its length. It is possible that the five participants reporting such times were referring to the completion of the feedback questionnaire.

Overall, with minor modifications, this measure was psychometrically acceptable, validated against published versions and generally acceptable by participants.

7.4.3 Recruitment Process

The recruitment rate for this pilot was low (6%) and less than the targeted mailshot approach used (10% overall) in the qualitative study (Chapter 5). SLTherapists were provided with a large number of packs (n=453). Of the thirty four SLTherapists who were approached only fifteen actively engaged with the researcher via email, so it is unclear how many were actively recruiting, although all ten geographical clusters were represented by the 15.

It was not possible to obtain feedback from non-consenting participants; however, feedback was sought from participating SLTherapists. All SLTherapists in the ten clusters were sent a link to brief anonymous online questionnaire containing five questions:

1. *What were the main challenges you experienced in recruiting?*
2. *Were the regular emails helpful/not helpful? Annoying?!*
3. *Did you make use of the recruitment reminder poster? If not any reason why?*
4. *Was there anything you think that could be done to make recruiting easier?*
5. *Any other comments welcome!*

The response rate was also low (14.7%) representing five individuals (see appendix 7.17). Respondents identified a number of challenges (Q1) relating both to themselves and to parents. From their perspective, time and forgetting due to competing demands and priorities were the main barriers.

“Time, and remembering to do it”

“My brain often feels at capacity when seeing families .. and appointments are often joint with other professionals which adds to the length of the appointment and the complexity of info given and received (and sometimes to how emotional the appointment is), sometimes I forgot to given out the pack or it felt inappropriate to give it.”

Therapists were also concerned about the load on parents. They did not want to overwhelm them with lengthy questionnaires particularly as they are already asked to complete a number of forms and evaluations by the SLT service. This also led to SLTherapists being selective about who to give a pack to over and above the inclusion/exclusion criteria.

“Not wanting to overwhelm families with too much information when you are already giving lots of info and possibly handouts regarding their child's .. difficulties. Needing to get them to complete other pieces of feedback..”

“..I was potentially too choosy about who I gave it to - I thought that only those parents I'd built up a good relationship with would complete the pack..”

The availability of suitable participants was also raised, with therapists referring to parents who may have literacy difficulties due to English being the second language or otherwise, and caseloads with a high number of children with safeguarding concerns.

"Lack of appropriate parents! Vast majority of parents of children on caseload have English as a second language, literacy difficulties, CP [child protection] concerns.."

All respondents found the regular emails received from the researcher (Q2) to be helpful at and the right frequency.

"Helpful, particularly because they were often positive."

Decisions as to whether to use the recruitment poster (Q3) seemed to be based on its usefulness and not all therapists used it.

"No I didn't use the poster as the brown envelopes were right by my computer - where I would have put the poster."

Sending the packs directly to parents was suggested as a better recruitment strategy (Q4), as it would help parents separate service and research demands. Other factors included the best place to store the packs so they would serve as a reminder and introducing competition between the clusters. The final suggestion was for parents to be able to complete them as soon as they received them.

"I think a number of families I saw went away with the best intentions of doing it, but family life got in the way. So maybe there's something there about being able to complete it on the spot."

There were no responses to the fifth question (Q5).

Feedback on the recruitment strategy indicates that both the demand placed on individual SLTherapists and participants will need to be considered in the main study. It will need to increase engagement with all SLTherapists and additional individual meetings may be beneficial. Responsibility for recruitment should rest with the researcher to ensure all available participants are provided with an opportunity to participate. Email reminders with positive messages were a useful strategy and should continue. Consideration should be given to direct contact with parents and methods to support parents to complete the measures 'on the spot'. To broaden the availability of suitable participants the methodology of the main study should consider literacy limitations.

7.5 Discussion

This pilot study assessed the acceptability of measures of adherence, satisfaction, self-efficacy and beliefs about SLCN to parents of children receiving SLT and evaluated the recruitment strategy. Twenty seven parents returned questionnaires and twenty were available to complete the final adherence measure over the telephone. Questionnaires were evaluated using descriptive statistics, measures of internal consistency, and, when two measures were purported to measure the same constructs were included, correlational analysis. Parents were asked to evaluate the questionnaires providing both qualitative and quantitative feedback. Recruiting SLTherapists (6.8%) responded to a brief, anonymous, online questionnaire. Qualitative responses were analysed using a thematic approach. The following measures were identified as appropriate for use in the main study with minor modifications: adherence: MATIF, satisfaction: CSPQ; self-efficacy: SE-SLTR and beliefs about SLCN: IPQR-SLCN. The recruitment rate (6%) was lower in comparison to the qualitative study (10%) and less than anticipated.

Adherence measures: The HRS II is a multi-factorial measure of homework completion with some support for its three components (Deane et al., 2012). The application of this three factor structure to the SLT population was uncertain as the subscales were not internally consistent. In addition, the 'Beliefs' subscales bears some similarity to the measures of the therapeutic alliance that will be used in the main study, risking duplication. The MATIF in contrast offers a single measure of adherence but one that is also specific to individual recommendations. It was given higher ratings of relevance by parents. The reference to specific recommendations was described as a limitation of the HRS II by parents. The single item 'quality' from the HRS II and the MATIF were significantly correlated indicating convergent reliability for the MATIF. The MATIF was also preferred due to its unique barriers section. The MATIF required a minor modification to enhance parents understanding of the instructions.

Satisfaction Measures: The CSPQ and the CSQ8 could not be differentiated psychometrically or through parent feedback, both were reliable, acceptable and quick to complete. The CSPQ was selected as it was specifically designed for use in SLT and has potential for future use in services. Convergent reliability with the CSQ8 supports its validation. Two questions were removed from the CSPQ to improve reliability, relevance and to reduce the length of the scale.

Self-efficacy measure: The questionnaire was designed for this study, required no amendments and was acceptable psychometrically and to parents.

Beliefs about SLCN: The identify and cause scales were modified using data obtained from a qualitative study (chapter 5) and as recommended by the original authors of the IPQ-R (Moss-Morris et al., 2002). Additional statements were also added to the Control and Consequences domains. Statements about SLTherapist and control were included as some parents in the qualitative study considered SLTherapists to have some responsibility for their child's progress. In the consequences domain this was to reflect the potential for the impact of SLCN on parents. Minor changes were indicated including the removal of the *SLTherapist-control* factor as this it was not internally consistent. This measure was psychometrically acceptable, validated against published versions and generally acceptable by participants.

Recruitment strategy: The low rate of recruitment (6%) was unanticipated. It was expected that participants may be more willing to participate if they had an established relationship with the recruiter. Knowing the recruiter may influence parents in accepting a pack of questionnaires but seemingly had limited effect in completing the measures once parents had left the clinic. Despite the large numbers of packs available, it is uncertain how many were given out and how many SLTherapists participated. Improving recruitment should therefore include increasing engagement with SLTherapists through individual meetings, minimising their responsibilities where possible, with the researcher taking primary responsibility for recruitment. Motivational and reminder emails should continue. The methodology in the final study should also consider an approach to responding to literacy difficulties within this population.

7.5.1 Limitations:

Recruitment did not yield the recommended sample size for pilot studies which limited the use of inferential statistics. A larger sample would have permitted the use of confirmatory factor analyses which would have been beneficial for examining the factor structure of the HRS II; however, this was not the only reason for not selecting this measure. Examining the factor structure of the Identity and Cause scales of the IPQR-SLCN and the CSPQ may have improved the measures further and so their factor structure will be explored in the main study.

This sample is highly selective and most certainly much more adherent than a general population sample, therefore the evaluation of questionnaires by participants on ease of completion, understanding and time to complete may have been artificially high.

The recommendations for the recruitment strategy are also based on a small sample; however, the feedback accords with published recommendations (Bower et al., 2009; Patel et al., 2003) and offers a specific insight into the experiences of SLTherapists and how their participation and therefore recruitment may be enhanced.

The CSQ8, although a widely published reliable and valid measure, is only available commercially. Whilst this was not the primary reason for choosing the alternative satisfaction measure, it was a consideration due to the limitations of a self-funded PhD. This should not be the basis for which scales are selected.

Conclusion

This pilot study confirmed the MATIF as the preferred measure of adherence, the IPQR-SLCN as a measure of illness perceptions and the CSPQ as a measure of satisfaction. The self-efficacy to follow recommendations measure was confirmed as both acceptable psychometrically and to parents. To obtain a greater understanding of the identity and cause scales of the adapted illness perceptions measure (IPQR-SLCN) and the satisfaction measure (CSPQ), an analysis of their underlying factor structure will be conducted on completion of data collection in the main study. This had not been possible during the pilot due to an inadequate sample size. Recommendations for enhancing recruitment will be incorporated into the main study.

CHAPTER 8

Phase 3: Method: cohort study

Overview of Chapter

The following chapter reports on the methods for the final empirical study in this thesis. This research was a prospective cohort study with follow up at eight months. A description of the design, participants, procedure, and a complete list of all measures is provided and the rationale behind the approach to statistical analysis included.

Ethical and Research and Development approval was obtained for this study: National Research Ethics Committee South Central - Oxford C (REC reference 13/SC/0341)

8.0 Study Aims

1. To identify levels of attendance at SLT sessions and parental adherence to individual treatment recommendations in two inner London Boroughs.
2. To determine the extent to which parental factors such as beliefs (illness perceptions, self-efficacy, expectations of treatment), experience of treatment (therapeutic alliance, satisfaction) and personal circumstances (family functioning, SES, practical barriers) relate to parent participation.
3. To determine the extent to which child characteristics relate to parent participation.
4. To identify whether attendance and adherence are related to child outcome.
5. To determine the extent to which parental factors (beliefs, experience of treatment, personal circumstances), child characteristics and actual treatment, relate to child outcome.

8.1 Design

In order to understand the motivational aspects of participation, participants were recruited at their child's first appointment with SLT and measures of parent beliefs, parent personal circumstances, child factors and anticipatory beliefs about treatment, completed soon after. For the measurement of attendance, adherence, parent experience of treatment and child outcome, follow-up was required. A six month follow-up was identified as meaningful as it was expected that within this time frame all participating children would have received treatment and that intervention effects were likely.

8.2 Participants

Participants were a consecutive sample of parents of young children (<5 years at recruitment) with an accepted referral to an inner London (Lambeth & Southwark) community SLT department over a 19 month period (August 2013 – February 2015). Families were excluded if their child had a chronic or current medical illness requiring regular active medical treatment. This is because when exploring parents beliefs, other health problems may potentially confound their perceptions of their child's SLCN, influencing the interpretation of the results. Also excluded were children who were receiving intervention primarily for eating and drinking difficulties as the type and frequency of intervention offered by SLT to this group differs

substantially from other types of SLCN. Participants were excluded if the child was subject to a child protection enquiry as this may have increased the risk to the researcher when visiting parents' homes. Family circumstances may also influence parental beliefs differentially to those without social services involvement.

Parents from all backgrounds were included and competency in spoken English was required (as judged by the local SLTherapist); those requiring the use of interpreting services were excluded. Data from the community NHS speech therapy department indicated that of 500 new referrals only 3% required the use of an interpreter and hence it was felt that a representative sample could be achieved without including parents who couldn't speak English. Competency in written English was not required as the quantitative questionnaires were read out to all participants. Both mothers and fathers were accepted as participants providing they described themselves as the primary mediator of the SLT intervention.

Qualified SLTherapists were provided with an information sheet containing study details, and accompanying script (appendix 8.1). Regular meetings were held (individual and group) with the SLTherapists to support their understanding and commitment to the research. Eligible parents were approached at their child's initial SLT assessment. The SLTherapist sought written consent from parents for the researcher to telephone them using a 'consent to contact' form (Appendix 8.2). Seven hundred and fifty eight families were asked, of which 58 did not meet inclusion criteria, 203 declined consent for initial telephone contact, 298 declined participation (or the researcher was unable to reach them) after giving consent for telephone contact. Recruitment proceeded steadily; lower rates sometimes coincided with holiday times (table 8-1). This resulted in a cohort of 199 parents who completed baseline measures and, following attrition, 148 parents who completed the follow up measures (figure 8-1). This gave a 35% recruitment rate, a 24% attrition rate following initial verbal consent and a 26% attrition rate at the second interview stage.

Of the total sample, one hundred and ninety participants were the mothers of the children and nine were fathers. Of those who dropped out of the study after the first interviews, forty nine were mothers and two were fathers. A sensitivity analysis indicated that there were no significant differences on any of the measures, treatment or demographic variables when fathers completed the questionnaires versus mothers, although caution is expressed due to the small sample size of fathers (appendix 8.3).

Table 8-1 Recruitment Summary

	Recruited	Completed Interview 1 & 2	drop out pre- interview 1	drop out post interview 1
Aug-13	14	9	3	2
Sep-13	11	6	3	2
Oct-13	28	15	6	7
Nov-13	13	8	2	3
Dec-13	18	9	4	5
Jan-14	22	14	2	6
Feb-14	17	9	5	3
Mar-14	12	6	3	3
Apr-14	18	8	4	6
May-14	14	6	6	2
Jun-14	18	13	4	1
Jul-14	0	0	0	0
Aug-14	18	11	2	5
Sep-14	18	8	7	3
Oct-14	7	4	3	0
Nov-14	10	5	4	1
Dec-14	4	3	1	0
Jan-15	10	6	3	1
Feb-15	10	8	1	1
TOTAL	262	148	63	51

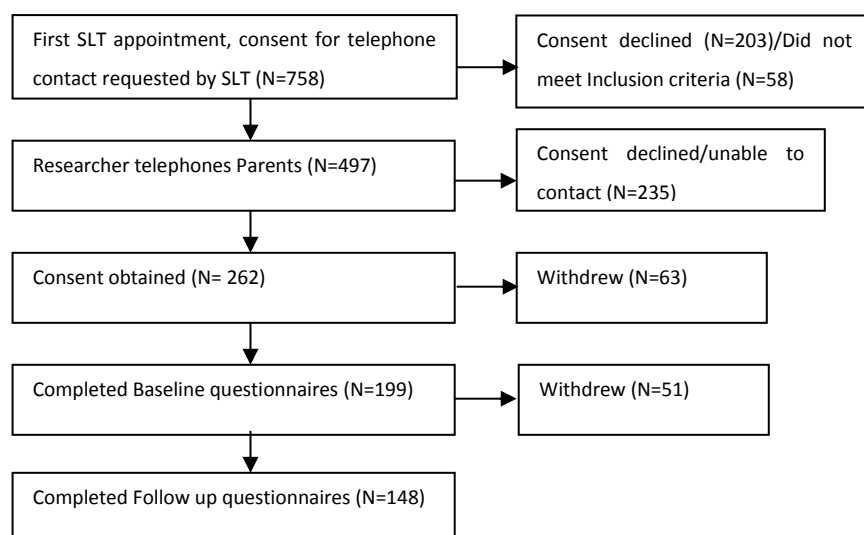


Figure 8-1 Recruitment and consent flow chart

8.3 Description of SLT service

The SLT departments of the two boroughs merged during the course of this study. Service delivery was overall equivalent across the two departments. The Early Years (EY) service is led and managed by senior SLTherapists (Band 8a). It is organised into geographical patches led by SLTherapists (band 7) and containing smaller clusters served by two to four SLTherapists. The clusters are led by one group member who takes overall responsibility for managing the caseload. In addition, SLTherapists also offer drop-in sessions and groups for all children (referred and non-referred) which offer generic parent child interaction (PCI) guidance, and general advice on stimulating speech, language and communication in young children.

The service offers an open referral system, meaning that anyone, including parents, could refer a child. Referrals are triaged by administrators who are able to contact senior SLTherapists to resolve any queries. Once accepted, children and their families are allocated to the closest cluster to their home and an appointment letter sent inviting them to an initial assessment. The letter asks them to contact the service to confirm the appointment or if the appointment offered is not suitable, and advises them that no contact will result in discharge.

For the majority of families, the initial appointment is a group assessment (exceptions are families requiring interpreters or children with high level needs identified in the referral). The group assessment is led by either two SLTherapists or a SLTherapist and SLAssistant. Parents are asked to bring a completed case history form which is then used as a basis for discussion with a SLTherapist. A short observation of the child is completed, including some interaction with a professional. No formal assessment of the child is carried out at this stage. A parent will then be advised if treatment is indicated or otherwise discharged.

The majority of children are offered a generic four week PCI intervention as the first step regardless of child or family need. From the service perspective this is used as a means of dynamically assessing a child whilst offering an intervention primarily aimed at changing parent behaviour. Following this, parents' are offered a review where formal assessment of a child may be undertaken and decisions on future intervention made. Families may be appointed to other specific groups for example for social communication development, or speech sound development. More rarely individual SLT may be offered, particularly for children who stammer. Most group interventions are 4-6 weeks long and a similar number of individual sessions are offered per 'block'. Over the course of their involvement with SLT

children typically receive a combination of interventions based on availability of resources and all parents receive recommendations for home practice.

If parents miss an appointment without notifying the department it will be recorded as a 'did not attend' (DNA). SLTherapists usually contact the parents directly but always send a letter to remind or rearrange the next appointment; the letter also indicates that should they miss another appointment, they will be discharged from the service.

8.4 Procedure

Participants were required to complete study measures at two time points. Baseline measurement averaged at one month (\bar{X} =5 weeks, SD 2.2) following their child's initial assessment and follow-up was typically eight months later (\bar{X} =7.7, SD 1.1).

Following verbal consent the researcher met the participants at a location of their choice, mostly their home (n=179, 89.9%), but also an NHS clinic (n=6, 3%), a local café (n=5, 2.5%), a children's centre (n=5, 2.5%), their place of work (n=3, 1.5%) and a park (n=1, 0.5%). During the telephone call participants were made aware of the aims of the study, their role and ethical issues including confidentiality. At the first meeting they were provided with an information sheet (appendix 8.4) and written consent was obtained. Seven questionnaires were completed during the first meeting and nine at the second (measures section 8.5). All measures were verbally administered allowing for the inclusion of participants who were competent in spoken English but perhaps not written.

The researcher did not have any direct involvement with any children in this study. All information relating to a child was provided either by the local SLTherapist, the parent or obtained from an electronic patient record. SLTherapists were asked to provide copies of all recommendations given to a parent, assessment results and outcome measures. Forty nine qualified SLTherapists were involved over the course of the research. The measures of child SLCN severity and outcome were part of usual practice in the SLT service. The measure of child SLCN severity was selected by the local SLT based on child need and presentation and was expected to be carried out on one occasion within the 6 month period. It was also expected that this would be completed as soon as possible after initial assessment. Following a child's initial assessment a SLTherapist would allocate the child and parent to an intervention in the

usual way, based on clinical judgement, local prioritisation guidelines and current availability of resources. The service routinely used Goal Attainment Scaling (GAS) as a measure of child outcome following intervention. On completion of the study, the researcher accessed electronic patient records and obtained attendance data and a minimal data set on any intervention received. This data set included number of sessions offered for assessment, intervention, type of intervention, mode of delivery and the number of SLTherapists involved with a child. Table 8-2 provides a summary of the involvement of parents, SLTherapists and researcher.

Table 8-2 Anticipated timeline for SLTherapist, parent, researcher involvement

	Recruitment: 4 weeks	Baseline: 6 weeks	Interim: 6 months	Follow up: 6-8 months
SLTherapist	Initial Assessment, approaches parent	Child Assessment	Copies of child information sent to researcher	
Parent	Parent agrees contact from researcher	Completes baseline measures		Completes follow up measures
Researcher	Consent obtained	Administers Baseline measures	Copies of child information received	Administers follow up measures, collects attendance and intervention data

8.5 Measures

The main method of obtaining data in this study was through the use of self/proxy-reported measures. This raised the possibility of additional bias being introduced which can contribute towards common method variance with the potential to influence findings through inflating reliability coefficients (Podsakoff et al., 2003). Response bias is where an individual answers questions falsely, either intentionally or unintentionally as a result of for example, social desirability (wanting to appear a certain way) or wanting to appear consistent through referencing back to previous answers. Participants may also be influenced by personal, but potentially inaccurate, theories between constructs.

In an attempt to address social desirability, participants were informed that there were no right or wrong answers, no judgement associated with any answer and that the researcher was simply interested in their view. They were informed that their child's SLTherapist would not know what they had said and reminded of the impartiality of the researcher (Podsakoff et al., 2003). Consistency bias was approached on the basis that being unable to see previous answers has been shown to reduce cross-checking by participants and hence potentially

reducing response bias (Peer & Gamliel, 2011). In this study, reading the questionnaires to participants meant that they were unable to check previous answers (dependant on scale length and participants' working memory). Items from different scales were not intermixed as this has the potential to increase context bias; participants may incorrectly attempt to relate the meaning of a current item with a preceding one which can influence correlation coefficients between two scales (Podsakoff et al., 2003).

Of particular importance in this study, given the diversity of the population invited to participate, was how item bias was addressed, that is how to minimise ambiguity and manage complexity of items so that participants do not apply their own idiosyncratic meaning. For questionnaires that were developed or adapted for this study, simplicity of language and concept was aimed for (Chapter 7); otherwise comprehension difficulties were addressed within interview. This also had an additional benefit of responding to unanticipated ambiguity. Items where this was a particular feature were: item one in the FLQ, the control subscale of the IPQRSLCN and to negatively worded items. The researcher responded consistently in her clarifications to all participants.

One final area of bias relevant here are measurement context effects (Podsakoff et al., 2003) as both the predictor variables and adherence outcome variable are obtained from same rater. This has the potential to produce spurious correlations between predictor and outcome variables due to the effects of response and contextual bias described previously. Podsakoff et al (2003) suggest that this effect can be minimised by the temporal separation of the measures which was the case in this study for baseline measures. For follow up measures, particularly those related to treatment experience, this remains a limitation.

8.5.1 SLTherapist completed Child Measures

As an indicator of problem severity, SLTherapists selected one of the following measures based on a child's primary need and were asked to provide copies of the results (table 8-3). The SLT department uses a range of assessments but SLTherapists were directed to use one of the following three measures to ensure consistency in measurement and to allow for comparisons across children. For children presenting primarily with language difficulties the Pre-school Language Scales (PLS) 4 UK Ed (Zimmerman, Steiner, & Pond, 1997) was selected. It is a standardised, norm-referenced measure of receptive/expressive language skills in infants and young children (2 weeks– 6.11 years). For children with primarily speech sound difficulties, the

Diagnostic Evaluation of Articulation & Phonology (DEAP) (Dodd, Hua, Crosbie, Holm, & Ozanne, 2002) was recommended. It detects and differentiates between articulation problems, delayed phonology and consistent versus inconsistent phonological disorder (normative data for children aged 3.0-6.11 years) and also provides standardised scores to facilitate comparisons. Finally, for children presenting with dysfluency, the percentage stuttered syllables in a language sample and a parent-rated severity rating was requested. Percentage syllables stammered is the most frequently used measure of severity in stammering research (Herder, Howard, Nye, & Vanryckeghem, 2006). The Lidcombe programme of early stuttering intervention (Franken, Kielstra-Van der Schalk, & Boelens, 2005) is the primary treatment for young children presenting with dysfluency in this particular department and includes the severity ratings.

The return rate for the SLT rated child measures of severity was low. One hundred and forty five children were described as having language difficulties and so it would have been reasonable to assume that they would have been assessed using a PLS but only 65 were returned (44.8%). Only one completed DEAP was returned; the screening section for another seven were received but could not be used due to the absence of a suitable metric with which to compare results. A measure of dysfluency severity was returned in two of the eleven cases described as presenting with this difficulty.

Table 8-3 Summary of SLTherapist-completed measures

	N		Mean (SD)	Range	z-skew
	Valid	Missing			
Child Problem severity measures					
Pre-School Language Scales (language)	65	80			
DEAP (speech)	1	35			
% syllable stammered/severity rating scale (dysfluency)	2	9			
Goal Attainment Scaling (GAS)					
Number of targets per child	102	97	1.82 (1.03)		2.45*
Targets Achieved (%)	102	97	82.5 (32.6)		-6.92
Change score (weighted)	102	97	18.7 (11.3)		-0.08*

*distribution assessed as normal

Child treatment outcome was measured using Goal attainment scaling (GAS) (Kiresuk et al., 1994)(table 8-3). It is a procedure whereby therapists set individual targets that are specific to the treatment provided at the beginning of an intervention. This universal rating system

permits comparison of child outcome across all communication difficulties and treatment types offered.

The return rate for outcomed GAS targets was less than anticipated (51.3%). A sensitivity analysis identified significant differences between participants with GAS targets and those without. Eighty eight completed targets were available for participants who completed the full study versus fifteen who dropped out following the first meeting, this association was significant ($\chi^2(1)=13.7$, $p < 0.001$) indicating that, if a person stayed in the study, they were 3.53 times as likely to have a completed set of GAS targets. Participants with completed GAS targets received more intervention ($\bar{X}=6.95$, $SE = 0.30$) than those without ($\bar{X}=4.71$, $SE=0.29$); the difference reached significance ($t(197)= 5.37$, $p<.001$) with a small to medium effect size ($r=0.36$). On average, parents identified more symptoms that they considered unrelated to SLCN (Mdn = 7) than those without (Mdn = 4), ($U=3774.0$ $Z=-2.90$, $p=0.004$) but with a small to medium effect size ($r=-0.21$). Receipt of GAS targets was not related to non-attendance ($U=4560.5$, $z=-.97$, $p = .33$) nor any other variables (appendix 8.5). These differences indicate that participants who had an outcomed GAS target available were unrepresentative of the whole sample. This measure was therefore not used in the main study. No other outcome measure specific to treatment was available. As an alternative, the follow up scores on the FOCUS provided a parent-rated child outcome measure.

8.5.2 Baseline Measures

Table 8-4 lists the names of the scales used at baseline.

Table 8-4 Baseline measures

Measure	Data Source
Demographic and background information	Parent
Illness Perceptions Questionnaire Revised-Speech Language Communication Needs	Parent
Family Life Questionnaire	Parent
Self-efficacy for Parenting Tasks Index-Toddler Scale	Parent
Self-efficacy- Speech Language Therapy	Parent
Parents Expectancies for Therapy Scale	Parent
Focus on the Outcomes of Communication Under Six	Parent

8.5.2.1 Demographic, and background information

Demographic and background information was obtained from the parent at the first meeting (Appendix 8.6) and included child data such as date of birth, family data including home post-code, siblings, marital status, age of parents, employment and education information. A number of indices of socio-economic status (SES) were used including capturing area deprivation derived from residential post codes (NPEU, University of Oxford Index of Multiple Deprivation Tool), and, at the level of the individual: final education level.

8.5.2.2 Illness Perceptions Questionnaire Revised-Speech Language Communication Needs (IPQR-SLCN)

This measure aimed to assess a parent's cognitive representations of their child's speech language impairment and is described in detail in the pilot study (Chapter 7) (appendix 8.7).

The first section (Identity scale) provides a list of thirty one symptoms judged to be related to the range of symptoms observed in children with SLCN (appendix 7.1). These symptoms represented the areas of expressive language, receptive language, speech, social communication, gesture, dysfluency, behaviour and learning. Following piloting, one symptom was added: *"Doesn't say speech sounds properly"* to capture children with speech problems but who remained intelligible. Parents were asked to rate on a dichotomous scale if the symptoms were present (minimum 0, maximum 31) and if they consider the symptoms to be related to their child's overall SLCN (minimum 0, maximum 31). Higher scores indicated more symptoms and a greater number related to SLCN.

The second section (parent views) examined illness perceptions across seven domains and included forty seven statements with a 5-point Likert response scale. The seven domains were i) timeline acute/chronic, ii) timeline cyclical, iii) consequences (all), consequences specific to parent, consequences specific to child, iv) personal control, with subdomains relating to how much control they believe their child has and they have, v) treatment control, vi) illness coherence, and vii) emotional representations. Higher scores indicate stronger agreement with statements endorsing how chronic their child's problem is likely to be (timeline), the cyclical nature of the communication problem (timeline cyclical) and the negative consequences of their child's problem, for them and their child (consequences). High scores on the personal control (including the perceived control a child or parent has over the problem), treatment

control and coherence dimensions represent positive beliefs about the how controllable their child's communication difficulty is and their personal understanding of their child's SLCN. Finally higher scores on the emotional representation section indicate a stronger endorsement of experiencing negative emotions. The following items were reverse scored: IP1, IP4, IP8, IP15c, IP15p, IP17c, IP17p, IP18, IP19, IP23, IP24, IP25, IP26, IP27, IP36.

The final section consisted of twenty nine causal attributions sourced from the original IPQ-R and the qualitative study (appendix 7.2). The 5-point Likert scale used to rate agreement was also converted to: causal belief endorsed (≥ 3) /not endorsed (≤ 2) allowing a total number of causes to be calculated.

8.5.2.3 Family Life Questionnaire (FLQ) (Chapter 6, Appendix 6.6) (J.Green personal communication)

The original FLQ was a measure of child and family functioning developed with parents of children with an autism spectrum disorder (ASD) and designed as an outcome measure following psycho-social communication interventions in ASD (Green, personal communication). It was designed to capture functionally important changes in family life. Items are rated on a five-point scale (1 = 'always', 5 = "never"). Once any negatively worded items were reverse scored, a higher score indicates poorer child and family functioning and a lower score suggests better functioning in the child and family (minimum 48, maximum 240). The four original constructs were re-examined in a factor analysis (chapter 9).

8.5.2.4 Self-efficacy for Parenting Tasks Index-Toddler Scale (SEPTI -TS) (Appendix 6.2) (Coleman & Karraker, 2003)

This self-rated self-efficacy scale measured parents' confidence in parenting skills across seven domains considered most relevant to parenting a young child (see Chapter 6). Six of the seven domains were retained in the present study: emotional availability, nurturance, discipline, play, teaching and instrumental care (e.g. "I have been successful in getting my child to eat on a fairly regular schedule."). Parents rated their agreement on a six-point Likert scale with higher scores indicative of greater confidence in one's own parenting skills. The protection subscale was not included in the present study.

8.5.2.5 Self-efficacy- Speech Language Therapy Recommendations (SE-SLTR)(Appendix 7.15)

The SE-SLTR was developed to examine a parent's judgement of their ability to carry out the recommendations made by their child's SLTherapist when faced with certain additional demands (Chapter 7). Nine barriers were listed and presented in the format: "I am confident that I can carry out the home-based activities with my child, that were recommended by the SLTherapist even if..." for example, a) I am tired or h) I have lots of other things to do. Parents were asked to rate their degree of confidence on a seven-point scale (1 = 'not at all confident', 7 = 'very confident'). The maximum score was sixty three and would indicate a high degree of confidence.

8.5.2.6 Parents Expectancies for Therapy Scale (PETS) (Appendix 6.4)(Nock & Kazdin, 2001)

This questionnaire was designed to measure parents' expectations of change before child psychotherapy intervention. It was modified for use in this study, resulting in a 20 item measure (Chapter 6). The adaptation retained the three components: credibility (e.g. "I believe that my child will improve quickly. "), child improvement (e.g. "How much do you believe the treatment will help you in being a parent? ") and parent involvement (e.g. "How much of a role do you believe that you will have in your child's treatment?"). Parents were asked to rate their answers on a five-point, Likert scale (minimum score 20, maximum 100); higher scores indicate greater positive expectations of therapy.

8.5.2.7 Focus on the Outcomes of Communication Under Six (FOCUS ©) (Appendix 6.8) (Thomas-Stonell et al., 2009)

The FOCUS is a reliable measure of changes in children's functional communication (real world communication and interaction skills in different contexts) following SLT (Thomas-Stonell et al., 2009). The fifty-item parent version was used; ratings are based on a seven-point Likert scale (minimum score 50, maximum 350). Higher scores indicate greater communicative competence. Items 24, 25, 29, 30, 32, 34 are negatively worded and hence reverse scored. The 'minimally clinical importance difference' (MCID) was set as a 16 point change in FOCUS scores.

8.5.3 Follow up measures

Table 8-5 lists the scales and information collected at follow up. All baseline measures* were repeated with the exception of the PETS.

Table 8-5 Follow-up measures

Measure	Data Source
Attendance data	Electronic patient record
Intervention data	Electronic patient record
Illness Perceptions Questionnaire Revised-SLCN*	Parent
Family Life Questionnaire*	Parent
Self-efficacy for Parenting Tasks Index-Toddler Scale*	Parent
Self-efficacy- Speech Language Therapy*	Parent
Focus on the Outcomes of Communication Under Six*	Parent
Working Alliance Inventory –Short	Parent
Barriers to Treatment Participation	Parent
Modified Adherence Telephone Interview Form	Parent
Consumer Satisfaction Parent Questionnaire	Parent

8.5.3.1 Attendance Data

To obtain non-attendance data electronic patient records were manually searched and sessions recorded as missed without prior notice counted. Converting this score into a percentage by dividing sessions missed by session offered was considered; however, this did not take into account the variation in the number of sessions offered by the SLT department. If percentage attendance were to be used, then a parent who attended two of four sessions would have the same percentage as one who missed five out of ten, potentially obscuring important differences. This approach was dismissed and a simple count of sessions missed (labelled as Did Not attend - DNA) used instead. The variability of sessions offered was accounted for in the analysis (see statistical analysis section: predicting attendance, for a full explanation).

8.5.3.2 Intervention Data

The intervention data set was obtained from electronic patient records pertaining to the child and included: number of sessions offered for assessment, intervention; type of intervention, mode of delivery and the number of SLTherapists involved. Information about any other diagnosis was also obtained at this time.

8.5.3.3 Working Alliance Inventory –Short (WAI-S) (Appendix 6.3)(Tracey & Kokotovic, 1989)

The Working Alliance Inventory–short (WAI-S) is a reliable, twelve-item, self-report instrument designed to reflect the theoretical underpinnings of the therapeutic alliance (TA) including the three components of task, bond and goal alliance (Horvath & Greenberg, 1989). Validity for the measure was supported through confirmatory factor analysis and using three goodness of fit indices. A copyright license was obtained from the original authors of the scale to permit its use in this study (appendix 6.3). Items are scored on a 7-point scale with higher scores indicating higher positive ratings of TA. Minor adaptations were made to the measure to increase its relevance for this population (Chapter 6).

8.5.3.4 Barriers to Treatment Participation (BTPS)(Appendix 6.7) (Kazdin et al., 1997)

This self-report measure was designed for use with parents of children and adolescents participating in psychological therapies to identify reasons for dropping out of intervention. Four *a priori* subscales of ‘competing activities/life stressors’, ‘relevance of treatment’, ‘relationship with therapist’ and ‘treatment issues’ were identified. Items were rated on a five-point scale (1 = ‘never a problem’, 5 = very often a problem’). Minor modifications (Chapter 6) resulted in a 41-item questionnaire. Across all subscales and the total barriers score higher scores indicate an increased perception of barriers to participating in therapy. In addition to the total barriers score the 5-point Likert scale used to rate agreement with statements was converted to: barrier a problem (≥ 2) / barrier never a problem (=1) allowing a barrier problem total to be calculated.

8.5.3.5 Modified Adherence Telephone Interview Form (MATIF) (Appendix 7.12) (Dreyer et al., 2010)

The MATIF was developed to evaluate parental adherence to recommendations with parents of children with ADHD (Dreyer et al., 2010) and, following the pilot study (Chapter 7), judged to be acceptable for use with parents of children with SLCN. This measure provided one of the two main outcome measures: degree of adherence. Minor modifications were made and the measure piloted, (Chapter 7). Parents were asked specific questions about each recommendation in turn, including rating how much they followed the recommendation and how important it was (using a five-point Likert scale). A list of barriers were provided that may have interfered with their ability to complete the recommendation and parents' asked to indicate which, if any, applied to their experience. An open ended question provided information about any other barriers not mentioned. Parents were asked to indicate if their child's behaviour had changed and to rate the level of improvement (or worsening if appropriate) from both theirs and their child's teacher's perspective. Ratings for all behaviour change questions were on a 5-point Likert scale (1= a little better/worse, 3 = better/worse, 5= much better or worse).

One of the two main outcome variables 'degree of adherence' (Dadh) was obtained from the question about how much they followed a recommendation. Dadh was calculated by transforming the 1-5 Likert scale to 0-4. These scores were then averaged, dividing the number of recommendations with the rate of adherence scored and further divided by four (the number of points on the transformed scale) and multiplying by one hundred to provide a rate of adherence. This is the approach recommended by the authors (Dreyer et al., 2010).

Recommendations were classed by the researcher into one of four categories (table 8-6)

Table 8-6 Recommendations classifications adapted for SLT

A: Active self-help: Parent to initiate or engage in some form of active self-help strategy.

B: Professional/non-psychological: Consult with a professional other than a SLT.

C: School-based: Involving the school, tutoring, or school academic-related programs.

D: SLT services: Any type of speech & language Therapy or another SLT evaluation.

8.5.3.6 Consumer Satisfaction Parent Questionnaire (CSPQ-SLT)(Appendix7.14)(Grela & Illerbrun, 1998)

The original 22-item questionnaire was developed by two SLTherapists and three parents with direct experience of SLT services. Piloting of the measure resulted in a 20-item version (Chapter 7). When completing the questionnaire participants were asked to rate their agreement with each statement using a 5-point Likert scale (1=Strongly Disagree, 3=No Opinion, 5=Strongly Agree). Higher scores reflected greater satisfaction with the service.

8.6 Statistical Analysis

All analyses were completed using the statistical software package SPSS version 22 (SPSS Inc. (2009)).

8.6.1 Factor Analysis

Factor analyses were conducted for the identity and cause scales of the IPQR-SLCN, FLQ and the CSPQ. For the two IPQR-SLCN scales, these items were predominantly generated from qualitative interviews with parents (Chapter 5) and as such are not theoretically driven. The FLQ was considered for factor analysis as it was developed for a different population and the original structure was not confirmed by factor analysis. Finally, the original CSPQ was not tested psychometrically but was piloted (Chapter 7) for use in this study. The sample size in the pilot was insufficient to undertake a factor analysis at that time.

The maximum likelihood factor analysis method using oblimin with Kaiser rotation was used as it was assumed that the underlying factors were related. The Kaiser-Meyer-Olkin (KMO) measure verified the sampling adequacy for the individual items as well as for the analysis. Items were removed if assessed as 'mediocre' (i.e. < 0.6) (Kaiser, 1974). A significant Bartlett's test of sphericity indicated that correlations between items were sufficiently large for factor analysis. Initial analyses were run to obtain eigenvalues for each factor in the data and to identify the number of components with eigenvalues over Kaiser's criterion of 1. Scree plots were examined for inflexions that would justify retaining factors. After rotation only items loadings above 0.40 -0.50 were included (Stevens, 2012).

8.6.2 Descriptive Statistics

Descriptive statistics, including the means, standard deviations and distribution of scores, were examined and screened to confirm if the assumptions for inferential testing were met. Values of skewness were converted into z-scores by dividing by their standard error, values between -3 and +3, and, combined with visual inspection of histograms, scatterplots and normal probability plots, provided evidence that distributions were normal (Field, 2005).

8.6.3 Management of missing data

At baseline there were few missing data points (<8) across a small number of participants (<5), largely due to the nature of the administration of the measures. The mean substitution approach was taken where the missing value was replaced with the mean of the scale or subscale from which it was drawn for that respondent (Tabachnick & Fidell, 2007). This approach was also applied to missed items in the follow up data for those who completed the second set of measures. Exceptions were applied to demographic variables. This approach is not without criticism, particularly in relation to multivariate analyses (Tabachnick & Fidell, 2007). After consulting a statistician, it was agreed that the risks were tolerable given the small number.

At follow up, a 26% attrition rate resulted in missing data for 51 participants. One participant completed a reduced set of measures and one participant completed the measures in the absence of the researcher, which also resulted in some missing data.

A sensitivity analysis was conducted comparing those who dropped out after completing the first measures and those who completed the study (appendix 8.8). Means were compared using a T-test, Mann Whitney or chi-squared test dependant on whether test assumptions were met. Significant differences were found in three variables: children were more likely to have been discharged from SLT in participants who dropped out of the study ($\chi^2(1)=24.0$, $p < 0.001$) with a small to medium effect size (Cramer's $V=0.35$) (Cohen 1988). Parents who dropped out of the study were more likely to miss an appointment ($U=2727.5$, $z=-3.02$, $p<.001$) with a small to medium effect size ($r=-.21$). And, those that completed the study endorsed a greater belief that their child had some control over their SLCN ($t(197)=-3.742$, $p < 0.001$, $r=0.26$) with a small effect size. There were no significant differences in any of the

demographic variables or in any other measures or their subscales. The listwise deletion approach to managing missing data is used; only cases with a complete set of data are analysed. The potential reduction in power was acknowledged.

8.6.4 Significance testing and effect sizes

Effect sizes and confidence intervals are reported along with significance levels. Effect sizes demonstrate the magnitude of an effect and interpretations are based on Cohen's (1988) descriptions: small ($\leq .2$), medium ($\leq .5$) and large ($\leq .8$) where the figure represents a proportion of the standard deviation (SD) (e.g. .2 refers to 2/10 SD). Confidence intervals specify a range within which the expected value of parameter can be found. Relying on significance levels alone can be problematic in providing real world interpretations of data, for example an effect size of .14 could still be significant but as the means between two groups would only differ by less than two SD the real world effect may be unimportant if the SD are small (Nakagawa & Cuthill, 2007). For some years now the recommended practice in psychology, other social sciences and biology is, to ensure that a measure of the precision of the effect, namely effect sizes and confidence intervals are also reported (Nakagawa & Cuthill, 2007; Thompson, 2002).

In an exploratory study such as this, correcting for multiple testing is recommended by some but not others (Bender & Lange, 2001). The Bonferroni method is a commonly cited approach; however, it too is not without criticism since by reducing the risk of type I errors (rejecting the null hypothesis when it is true), type II errors (incorrectly accepting the null hypothesis) are necessarily increased (Perneger, 1998). This method of adjustment can also be considered as too conservative (Noble, 2009). Instead only effect sizes greater than .2 were considered of interest even if significance exceeded the pre-defined level of $p=.05$.

8.6.5 Inferential Statistics

8.6.5.1 Correlational analysis

The relationships between the independent variables and dependant variables of non-attendance, adherence to recommendations and child outcome, were examined to identify variables with significant relationships. Due to the suspected overlap in measures the relationships between the predictor variables were also assessed. When two variables were continuous, normally distributed and with no significant outliers Pearson's correlation was used. Otherwise Spearman's Rho was used.

8.6.5.2 Regression analyses

As per the study aims, independent variables were classified into four domains: 'parent beliefs', 'Parents personal circumstances', 'child characteristics' and 'Parents experience of treatment' (table 8-7). Data relating to parent beliefs and child characteristics were collected at baseline; the experience of treatment and personal circumstances domains contained variables from both baseline and follow up data which were treated separately. Multiple regression analyses were used to identify the relative contribution of each of the significant factors in predicting non-attendance, adherence to recommendations and then to child outcome. Domains were explored individually first then combined into a full model for predicting each outcome.

A number of predictors of attendance, adherence and outcome with weak associations were anticipated and as such a sample size with the power to detect small to medium effect sizes was considered appropriate. A sample size of 194 would be sufficient to detect correlations greater than .2 with 80% power and, within a regression, a sample size of 200 with twelve predictor variables would be sufficient to detect changes in R^2 greater than 5% (Field 2009). This study therefore aimed to obtain a final sample size of 200.

Table 8-7 Categorisation of measures and subscales into four domains

Parent Personal Circumstances	
<i>Baseline</i>	Maternal education level, Age, Employment. Area Deprivation Score. FLQ: Impact on Family Life (pre).
<i>Follow up</i>	BTPS: Competing Activities/Life Stressors. FLQ: Impact on Family Life (post).
Parents Beliefs	
<i>Child Problem Related</i>	IPQRSLCN: Timeline acute/chronic, Timeline cyclical, Consequences (total, child & parent), Personal control (total, child & parent), Illness coherence, Emotional representations
<i>Parental self-efficacy</i>	SEPTI-TS: Emotional availability, Protection, Nurturance, Discipline, Play, Teaching, Instrumental care, Total. SE-SLTR. FLQ: Confidence in helping child.
Child Characteristics	
	IPQRSLCN Identity: Total No. Symptoms, Symptoms Related to SLCN, Externalising behaviour symptoms, Language Difficulties, ASD Social Communication symptoms, Other behaviour symptoms. FOCUS baseline. FLQ: Child communication, Child social competence.
Treatment Experience	
<i>Baseline</i>	IPQRSLCN: Treatment control (pre). FLQ Treatment Experience (pre). PETS: credibility, child improvement, parent involvement, total score.
<i>Follow up</i>	IPQRSLCN: Treatment control (post). FLQ Treatment Experience (post). WAI: Task, Goal, Bond, Total. BTPS: Relevance of Treatment, Relationship to SLT, Treatment issues, Total. MATIF: importance of recommendation, barriers to a recommendation. CSPQ: Initial experience of SLT, Satisfaction, Parental Role in Treatment, Therapist Support, Total.
Child Outcome	
	FOCUS Follow up Score

Predicting Non-Attendance

The outcome variable (named DNA), in common with count data distributions, was positively skewed ($z\text{-skew} = 7.36$) and bounded by zero. If parametric tests with assumptions of normality were applied to this data, it would result in a poor fit, including biased significance tests (Gardner, Mulvey, & Shaw, 1995), but data transformation could be considered. In data that is bounded by zero and with a potentially large number of zero's, transformations are problematic and can result in nonsensical predictions such as negative numbers of events or

behaviours (O'Hara & Kotze, 2010). Transformed count data also perform poorly in comparison to untransformed data used in general linearised models (GLM)(O'Hara & Kotze, 2010). GLM's allow the specification of distributions other than normal such as Poisson. The Poisson distribution differs from a normal distribution in a number of ways including that it is a discrete rather than continuous distribution and that it counts only zero and positive integers rather than numbers from negative to positive infinity (Coxe, West, & Aiken, 2009). These models also provide a method to account for variability in exposure, which in this study relates to the number of appointments offered. This model was suited to describing the count variable 'DNA' and a regression analysis using a GLM was therefore used.

Model assumptions and fit were checked. A one sample Kolmogorov-Smirnov test was run on the distribution of 'DNA' which was non-significant ($p = 0.096$) providing evidence to state that it was a Poisson distribution. Observations were independent. The Poisson distribution requires only one parameter to be specified (equivalent to both the mean and variance), in contrast to a normal distribution, which requires both to be stated. The Poisson distribution therefore assumes that the mean and variance are equal (Gardner et al., 1995). Where this is not the case and over dispersion is present, this can lead to overestimated significance and reduced confidence intervals and an alternative model, the negative binomial, is recommended (Cox et al 2009). In this study a comparison of the mean (1.94) and variance (3.41) provided evidence of over-dispersion indicating that a negative binomial regression should be considered.

In a negative binomial regression the data remains modelled on the Poisson distribution but an additional parameter is added to account for over dispersion. It is similar to the error term found in linear regression and accounts for heterogeneity not accounted for by the variables of interest (Coxe et al., 2009). In this study the negative binomial regression was initially run with the overdispersion parameter set at 1; however, this resulted in poor model fit (goodness of fit indicator 'deviance value/df' was outside expected values of between 0.9-1.1 (Atkins et al 2014)). Directly estimating the overdispersion parameter gave values of between 1.18 and 2.26 and the 'deviance value/df' improved to acceptable values (Crowson 2015). The results of the Poisson and Negative Binomial Regressions for each area of interest were compared for goodness of fit: the Akaike's Information Criterion (AIC), and Bayesian Information Criterion (BIC) were both reduced in the negative binomial model and the deviance value/df improved, providing evidence that this model was the preferred model for each regression.

In other types of regressions such as ordinary least squared, R^2 can be used to explain the amount of variation a model can account for, it is also used to provide evidence that a model is preferred over the null model i.e. without any predictors. In logistic regressions such as Poisson or negative binomial the R^2 metric is not available as these models use maximum likelihood estimates as a result of an iterative process. As a work-around a pseudo R^2 (McFaddon's) was calculated to allow a crude assessment of model fit and to support lay understanding when interpreting the results.

Predicting adherence to SLT Recommendations

The outcome variable 'degree of adherence' (Dadh) was obtained from the MATIF and calculated following the same procedure as the original authors (Dreyer et al., 2010). A forward stepwise linear regression was planned using variables that demonstrated significant correlations with the outcome variable Dadh.

Each regression was checked to ensure that all assumptions were met. A one sample Kolmogorov-Smirnov test was used to assess the normality of the residuals and case-wise diagnostics examined to observe the influence of any outliers on the distributions, cases were removed where necessary to provide a normal distribution. A Durbin-Watson statistic between 1-3 (closest to 2) was used to confirm the independence of the observations (Field 2009). Homoscedasticity and linearity were checked using scatter plots of standardised predicted values and residuals. Multicollinearity was assessed through correlations between predictor variables, where, if present, a value of $r > .9$ would have been expected. Variance inflation factor (VIF) collinearity and tolerance statistics also provided evidence for an absence of multicollinearity.

Predicting Child Outcome

The variable 'FOCUS follow up score' was used as the independent variable. A multiple linear regression was planned using variables that demonstrated significant correlations with the outcome variable 'degree adherence'. To take account of the effects of baseline scores on the FOCUS this was entered as a predictor variable in the first block of each regression. The same approach as for predicting Dadh was used in checking the assumptions for the regression (see above).

CHAPTER 9

Results: Cohort Study

Overview of Chapter

This Chapter reports the findings of the cohort study. It begins with a description of the sample (parents, children and intervention received) followed by a section on the reliability of the measures. The descriptive statics are provided for all scales including the primary outcome measures (answering Aim 1). Inferential statistics focus on responding to the remaining study aims of predicting attendance, adherence and finally outcome. Post Hoc analyses are included aiming to characterise participants further based on the primary predictors of attendance and adherence.

9.1 Description of the Sample

Summary statistics for the children's parents are in table 9-1, those for the children in table 9-2 and a summary of interventions received by the children can be located in tables 9-3 and 9-4.

9.1.2 The children's parents

The average age of the children's mothers' was thirty four (SD 5.88). Participants spoke a range of different languages with forty one languages represented in the sample (table 9-1). Almost equal numbers of participants spoke either just one language (49.2%) or multiple (49.7%). Competency in spoken English was a requirement for participating in the research but some participants (27.1%) stated that English was not the primary language used at home. A range of ethnicities was represented across the group with the largest maternal ethnic group being 'black or black British' (50.3%) followed by 'white' (40.7%). There was an over representation of 'black or black British' ethnic group in comparison with the local populations of the two boroughs from which the sample was drawn (Southwark Demography Bulletin 2015, Lambeth Council 2014). The sample was spilt into two groups to allow the effects of ethnicity to be explored (1. white and 2. black or minority ethnic (BME)).

The sample was drawn from the 8th and 12th most deprived boroughs in London and 14th and 41st in England (National Census 2011); however, participants came from all backgrounds; with only the highest group not represented. The actual scores were normally distributed (z-skew - 0.11) but, when reclassified into quintile groups, the majority were classified into one of the more deprived groups (four). The distributions of both the quintile group membership as well as actual deprivation scores were examined for the purpose of describing the sample, with only the actual deprivation scores were used in the analysis. Information was missing for five participants as their postcodes were not recognised by the IMD tool (<https://tools.npeu.ox.ac.uk/imd/>). Parents were educated to varying levels from no qualifications to postgraduate degrees with the data normally distributed (Z-skew: -2.34). Slightly more mothers were not working (53.7%) than currently employed (46.3%); of those who were in work (n=92) 45.7% worked full-time. The majority of children were in a two-parent family setting (62.3%) and the average number of people living in the home was four (SD 1.33, range 1-10).

Table 9-1 Characteristics of the family

Variable	n (f %)	M (SD)	Range	Z-Skew
Age of Mothers (years):	193	34.4 (5.88)	22-47	-0.77*
Languages represented (N=197)	41**			
Languages spoken in home (N=197)				
1	98 (49.2)			
2	84 (42.2)			
3	15 (7.5)			
English Primary	143 (71.9)			
English Secondary	54 (27.1)			
Ethnicity (main ethnic group maternal) (N=199)				
White	81 (40.7)			
Asian or Asian British	6 (3)			
Black or Black British	100 (50.3)			
Mixed	8 (4)			
Other Ethnic groups	4 (2)			
Area Deprivation Code	194	31.4 (8.45)	10.9-53.8	-0.11*
Area Deprivation Quintile Group (summary) (N=194)				-4.77
1 (\leq 8.49 Least deprived)	0			
2 (8.5 - 13.79)	6 (3)			
3 (13.8 - 21.35)	17 (8.5)			
4 (21.36 - 34.17)	105 (52.8)			
5 (\geq 34.18 Most deprived)	66 (33.2)			
Highest Education Level (maternal) (N=198)				
0 (none)	14 (7)			
1 (1-4 GCSE passes at GSE, GCSE, O level)	29 (14.6)			
2 (\geq 5 passes at GSE, GCSE, O level)	30 (15.1)			
3 (A levels or equivalent)	48 (24.1)			
4 (University)	59 (29.6)			
5 (Postgraduate degree)	18 (9)			
Employment status				
Mothers (N=199): in work	92 (46.3)			
Not working	107 (53.7)			
1-parent family (N=199)	75 (37.7)			
2-parent family (N=199)	124 (62.3)			
Number living in house (N=199)	199	3.94 (SD	1-10	9.22

*distribution assessed as normal ****Languages spoken:** Acholi, Amharic, Arabic, Bulgarian, Calaba, Creole, Czech, Edo/Bini, English, Esan, Fanti, Finnish, French, German, Greek, Hausa, Hungarian, Igbo/Ibo, Italian, Kirundi, Krio, Lingala, Lithuanian, Ndebele, Norwegian, Patois, Polish, Portuguese, Russian, Slovak, Somali, Sorolan, Spanish, Swedish, Telegu, Tigrinya, Turkish, Twi, Urdu, Wolof, Yoruba.

9.1.3 The children

The number of males in the study was significantly higher than females, both at the start of the study (males n=153, females n=46) and in the final cohort (males n=133, females n=35); the ratios of 3.3:1 and 3.8:1 indicate an overrepresentation of boys in this sample.

The average age of the children was thirty seven months (range 15-59 months, SD 9.74); the distribution was positively skewed towards children being younger. This distribution was comparable to published SLT caseload characteristics from a similarly deprived area in the UK (Broomfield & Dodd, 2004). There was a greater proportion of children classified by parents as being of mixed ethnicity (14.1%); however, in common with their parents, the main ethnic group was 'Black/Black British' (48.7%) followed by 'white' (33.7%).

Electronic patient records were reviewed to obtain information about a child's SLCN and any other diagnosis. The notes provided descriptions of the nature of a child's SLCN and in total nine terms were used; an additional category of 'none' was added for the purpose of this study (table 9-2). A single description was applied to the majority of the children (n=125, 62.8%) and others were given multiple descriptions (n=74, 37.2%). The most common additional diagnosis was autism spectrum disorder (11.6%) but the majority (79.4%) did not have any reported additional problems. Language problems was the most frequently named difficulty mentioned on 145 occasions followed by speech problems (36 occasions) and dysfluency (11 occasions).

Table 9-2 Characteristics of children

Variable	n (f %)	M (SD)	Range	Z-Skew
Age of children (months):	193	37.1	15-70	4.12
Sex				
Male	153 (76.9)			
Female	46 (23.1)			
Ethnicity (main ethnic group child) (N=199)				
White	67 (33.7%)			
Asian or Asian British	3 (1.5%)			
Black or Black British	97 (48.7)			
Mixed	8 (4)			
Other Ethnic groups	4 (2)			
Number of SLCN descriptors given (N=199)				
0	1 (0.5%)			
1	122 (61.3%)			
2	73 (36.7%)			
3	3 (1.5%)			
Single SLCN Descriptor given (N=199,)				
1. Speech	23 (11.6%)			
2. Stammer	8 (4%)			
3. Mixed Language:	75 (37.7%)			
4. Expressive Language	6 (3%)			
5. Selective mutism	1(0. 5%)			
6. Attention & Listening problems (AL)	0			
7. Social Communication (SC)	1 (0. 5%)			
8. Specific Language Impairment (SLI)	8 (4%)			
9. Eating & Drinking (late description)	1 (0. 5%)			
10. None	2 (1%)			
Combinations of multiple descriptors given (N=199):				
1. Mixed language & SC	44 (22.1%)			
2. Mixed language & AL	11 (5.5%)			
3. Mixed language & speech	4 (2%)			
4. Speech & expressive Language	5 (2.5%)			
5. Expressive language & AL	2 (1%)			
6. Expressive & SC; speech & stammer; stammer & expressive, AL & speech	Each combination: 1 (0. 5%) Total 4(2%)			
7. Expressive, AL and social communication; expressive, speech & stammer; mixed lang, AL, speech; mixed lang. SC, AL.	Each combination: 1(0. 5%). Total 4(2%)			
Other Diagnoses (N=199)				
1. ASD	23 (11.6%)			
2. ADHD	2 (1%)			
3. Motor delay	1 (0.5%)			
4. Global Dev. Delay	4 (2%)			
5. Cerebral Palsy	1 (0.5%)			
6. Glue Ear	3 (1.5%)			
7. Turners Syndrome	1 (0.5%)			
8. Downs Syndrome	2 (1%)			
9. Ex prematurity	3 (1.5%)			
10. Seizures	1 (0.5%)			
11. None	158 (79.4%)			

9.1.4 Intervention received

Over a period of 6-8 months, the participants and their children were offered an average of nine sessions (range 1-20) of which three were typically for assessment (range 1-7) and six for intervention (range 0-16)(table 9-3). The most frequent form of intervention offered was a four week generic Parent Child Interaction (PCI) group, with one hundred and thirty seven families (68.8%) being offered this regardless of child difficulty. Families waited on average 52 days for intervention to start following their initial assessment, although there was a wide range (1-247 days). All distributions for these variables were positively skewed. Across the whole sample the service offered 1767 appointments in total, 378 were missed by participants giving an overall level of non-attendance of 21.4% over the period of study.

Table 9-3 SLT appointments, waiting times and discharge

Variable	n (f %)	M (SD)	Range	Z-Skew
SLT Appointments (N=199)				
Total Sessions offered (per participant)		8.92 (1.32)	1-20	2.17*
Assessment		2.95 (1.32)	1-7	3.57
Intervention		5.97 (3.15)	0-16	2.64*
Overall Sample: Sessions missed		2.0 (1.9)	0-8	6.64
Waiting time: assessment to intervention (days)	185 (93%)	52.2 (36.5)	1-247	10.2
No. SLTherapists involved		2.0	1-4	
Discharged from service	79 (39.7%)			
Discharge reasons:				
1. Intervention no longer required	16 (8%)			
2. Parent declined (direct/indirect)	49 (24.6%)			
3. Moved out of area	8 (4%)			
4. School age (school don't commission SLT service)	6 (3%)			

*distribution assessed as normal

Interventions were classified relative to the main targeted area of need (table 9-4). Ninety-seven children received a single type of intervention the remainder (n=90) received more than one. The twelve children who did not receive any direct intervention with a SLTherapist had a range of SLCN descriptions applied: speech (2), stammer (2), mixed language (4), expressive language (1), selective mutism (1), SLI (1) and none (1). Where children received more than one type of intervention the combinations of these were examined by two senior speech & language therapists (PW & VS). A very small proportion (n=7, 0.4%) could be considered slightly unexpected as a combination but not implausible, for example vocabulary development activities followed by work on articulation, or a generic parent child interaction

group offered following by eating and drinking intervention. Therefore, combinations of interventions appear acceptable from the perspective of a SLTherapist.

A proportion of these combinations crossed classes of intervention, for example beginning with a language intervention and then changing to a parent child interaction (PCI) intervention. For those who started with a speech intervention, there was a single occurrence (5%), starting with a language intervention, two occurrences (14%), social communication four occurrences (27%) and for those starting with PCI (typically a generic group), a single change occurred in twenty one cases (15%) and more than one in five cases (4%).

Table 9-4 Type of interventions offered by class

Class of Intervention	No. receiving single class n (% of total)	Total receiving this intervention
A: Speech	7 (38.9%)	18
B: Language	7 (50%)	14
C: Social communication	6 (40%)	15
D: Parent Child Interaction (PCI) – generic group	67 (50.4%)	133
D: PCI - individual	5 (3.8%)	
E: Stammering	5 (83.3%)	6
G: Eating & Drinking	0	1
Class of intervention different (1 st & 2 nd)		
Yes: 58 (29.1%)		
No: 32 (16.1%)		

9.2 Reliability of Measures

9.2.1 Factor analysis

Factor analyses were conducted for the identity and cause scales of the IPQR-SLCN, the Family Life Questionnaire (FLQ) and the consumer satisfaction questionnaire (CSPQ).

9.2.1.1 IPQR-SLCN Identity Scale

A factor analysis, using the maximum likelihood method using oblimin with Kaiser rotation, was initially conducted on the 31 items of the identity scale. The KMO measure verified the sampling adequacy for the individual items as well as for the analysis. Seven items were removed (numbers 1, 2, 3, 4, 5, 14, 15) as all were considered 'mediocre' (< 0.6) (Kaiser 1974). A factor analysis was run on the remaining 24 items. Once these items were removed the KMO for the analysis was 0.78 which was acceptable. Bartlett's test of sphericity ($\chi^2(276)=988.0$ $p<.001$) indicated that correlations between items were sufficiently large for factor analysis.

An initial analysis was run to obtain eigenvalues for each factor in the data. Seven components had eigenvalues over Kaiser's criterion of 1 and in combination explained 54.8% of the variance. The scree plot showed an inflexion that would justify retaining four factors. Table 9-5 shows the factor loadings after rotation. Only items loadings above 0.45 were included ($>.4$ is typical, Stevens, 2012). All four appeared coherent with factor one representing externalising behaviours, factor two language difficulties, factor three referring to other behaviours and factor four representing an ASD social communication phenotype. Factor two showed an acceptable internal reliability (Cronbach $\alpha=.75$). Factor's one and three were questionable (Cronbach $\alpha= .68, .63$) and factor four showed poor reliability (Cronbach's $\alpha=.41$). This four factor solution explained 41.2% of variance. The seven items that were removed represented speech, stammering, understanding, and interaction style symptoms. At least 53% of the children were identified by a SLTherapist as having difficulties where these symptoms are likely. It was therefore prudent to retain a total symptoms score as a measure, representing all of the original 31 symptoms.

Table 9-5 Structure Matrix:IPQR-SLCN Identity scale

Structure Matrix: IPQR-SLCN Identity Scale					
	Symptoms	Factor**			
		1	2	3	4
		External Behaviour	Language	Other	ASD/social
6	Reduced vocabulary/has few words				0.51
7	Doesn't ask questions		-0.78		
8	Doesn't name objects		-0.64		
9	Doesn't put words together into sentences		-0.74		
10	Repeats what is said (when not asked to)				0.46
19	Plays with objects repetitively or intensely				0.48
20	Rocks, flaps hands or makes other unusual movements			-0.69	
23	Sleep problems			-0.64	
24	Difficulties taking him/her on public transport			-0.47	
26	Aggressive	0.46			
28	Problems with attention/concentration	0.68			
29	Impulsive, does things without thinking	0.67			
31	Doesn't sit still	0.57			

****Items in BOLD included in factor**

9.2.1.2 IPQR-SLT Cause Scale

A factor analysis, using the maximum likelihood method using oblimin with Kaiser rotation, was initially conducted on the 29 items of the cause scale. Verifying the sampling adequacy for the individual items using the KMO measure identified items 1, 3, 7 and 9 as 'mediocre' (<0.6) and they were removed (Kaiser 1974). A factor analysis was run on the remaining 25 items and resulted in a KMO of 0.82, which was acceptable. Bartlett's test of sphericity, $\chi^2(300)=1822.72$, $p<.001$, indicated that correlations between items were sufficiently large for factor analysis.

An initial analysis showed seven components with eigenvalues over Kaiser's criterion of 1 explaining 62.67% of the variance. The scree plot showed an inflexion that would justify retaining four factors. Table 9-6 shows the shows the factor loadings after rotation. Only items loadings above 0.5 were included (>.4 usual, Stevens 2012). Of the four factors, factors two, three and four appeared coherent with factor two representing self-blame, factor three early medically related causes and factor four child-related. Factors two and three showed acceptable internal reliability (Cronbach $\alpha=.75$, .82). Factor four showed questionable reliability (Cronbach's $\alpha= .61$). The majority of items loading onto factor one related to external causes with the exception of one item "by stress or worry". Participants'

interpretation of this item was ambiguous, either viewed as parental stress/worry or child's stress/worry. Following consultation with experts on the IPQR cause scale this item was removed to improve the coherence of this subscale. Removal of this item did not affect the internal consistency of this factor (Cronbach's α pre .82, post .80). This analysis resulted in a seventeen item scale with four factors: 1. External causes (6 items), 2. Self-blame (3 items), 3. Early medical experiences (5 items) and 4. Child related (3 items).

Table 9-6 Structure Matrix:IPQR-SLCN Cause scale

Structure Matrix: IPQR-SLT Cause Scale					
	Causes	Factor**			
		1	2	3	4
		External	Self-blame	Early Medical	Child related
C2	By my child’s personality e.g. is shy				0.56
C4	By my child’s lack of experience with other children				0.57
C5	By my child’s emotional state				0.53
C10	By my own behaviour e.g. I didn’t do enough/the right things		0.66		
C11	By my emotional state e.g. feeling down, lonely, anxious, empty.		0.72		
C12	Because of family changes e.g. moving house, marital breakup, unhappy home.		0.67		
C14	By problems during pregnancy.			0.53	
C15	Because my child was born prematurely			0.63	
C16	By my child being in hospital for a long time			0.87	
C17	Because of the tube my child had in his/her throat			0.87	
C18	By my child’s surgery	0.59		0.62	
C21	Because my child has a problem with his/her tongue	0.60			
C22	By being given vaccinations e.g. MMR	0.54			
C24	By stress or worry*	0.63			
C25	By a germ or virus	0.76			
C26	By diet or eating habits	0.57			
C28	Because of pollution in the environment	0.60			
C29	Because of accident or injury	0.73			

**Items in BOLD included in factor

9.2.1.3 Family Life Questionnaire (FLQ)

The FLQ (J.Green, personal communication) is a measure of child and family functioning for parents of children with an autism spectrum disorder (ASD). The original questionnaire was divided into four domains: 1. Experience of being a parent of a child with Autism, 2. Family life, 3a. Child development, b. Child understanding, c. Child social relationships. 4. Child symptoms: a. Child feelings, b. Child behaviour and a total score. It was considered prudent to conduct a factor analysis in the present study as the original measure was designed for a different population and the domains were not previously confirmed by factor analysis. Obtaining a greater understanding of the factor structure would also be beneficial given the potential overlap in content with other measures used in this study. Of particular interest in this study was the subdomain of family life as a measure of parent personal circumstances.

A factor analysis, using the maximum likelihood method using oblimin with Kaiser rotation, was initially conducted on all 44 items. Following KMO verification of sampling adequacy for the individual items as well as for the analysis, items 3, 15, 23, 43 were below 0.6 and considered 'mediocre' (Kaiser 1974); these items were removed. The factor analysis was run on the remaining 39 items resulting in an acceptable KMO of 0.82. Bartlett's test of sphericity ($\chi^2(946) = 3570.6$ $p < .001$) indicated that correlations between items were sufficiently large for factor analysis.

An initial analysis was run to obtain eigenvalues for each factor in the data. Twelve components had eigenvalues over Kaiser's criterion of 1 and in combination explained 63.6% of the variance. The scree plot showed an inflexion that would justify retaining five factors. Table 9-7 shows the factor loadings after rotation. Only items loadings above 0.45 were included with the exception of item 40, where the lower loading was included in Factor 1 to improve the coherence of the scale and to ensure sufficient items were available for that factor. All five factors appeared coherent with factor one representing child communication, factor two impact on family life, factor three confidence in helping child with SLCN, factor four representing child social competence and factor five treatment experience. All factors demonstrated acceptable internal reliability (Cronbach $\alpha = .70$ to $.90$). This five factor solution explained 44.0% of the variance.

Table 9-7 Structure Matrix: FLQ

Structure Matrix: FLQ						
		Factor**				
		1	2	3	4	5
1	I lack confidence in knowing how to help my child			0.62		
4	I am confident that I understand my child's level of development			0.60		
5	I feel I know how to help my child progress			0.62		
6	I feel I'm getting it wrong			0.55		
8	I doubt my ability to help my child's development			0.68		
9	I feel frustrated at not knowing how to help my child			0.65		
10	I have coping mechanisms to help my child			0.53		
2	I feel listened to by professionals					0.52
11	Professionals don't understand my family's needs					0.63
12	It's a continual battle to get the right help for my child					0.61
13	My child is getting the right help					0.48
17	Family life is calm		0.51			
18	I know how to cope with my child when going on an outing in a public place e.g. café or restaurant		0.56			
19	I feel confident to go out to family events with my child		0.64		0.46	
30	My child has repetitive behaviour and sensory interests that make it difficult to go on an outing		0.76			
37	My child is calm		0.56			
39	My child is unpredictable		0.51			
44	My child is embarrassing when going out		0.66			
45	My child has repetitive behaviours make day to day life impossible		0.78			
24	My child can spontaneously begin communication with me	0.82			0.55	
25	My child spontaneously begins communication with other members of the family	0.99			0.49	
40	My child can let me know what he/ she is upset about	0.45			0.72	
26	My child can request his/ her needs appropriately				0.68	
28	My child can let me know when he/ she is hurt				0.62	
31	My child is good at sharing with others				0.54	
33	My child is aware of other people's needs				0.64	
41	My child understands appropriate behaviour in familiar social situations				0.71	
47	My child plays with other children				0.60	

**Items in BOLD included in factor FACTORS: 1: child communication 2: impact of family life 3: confidence to help 4: child social competence 5: treatment experience

9.2.1.4 Consumer Satisfaction Parent Questionnaire (CSPQ)

Initially developed in a SLT context, the original 22 item measure was organised into seven themes: referral process, service convenience, assessment process, parent intervention, parent support, intervention format, and parent satisfaction (Grela & Illerbrun 1998), although not psychometrically validated. This measure was piloted (Chapter 7) resulting in the 20-item scale used in the present study. A factor analysis was undertaken to explore underlying latent constructs.

A factor analysis, using the maximum likelihood method using oblimin with Kaiser rotation, was initially conducted on all 20 items. The KMO measure verified the sampling adequacy for the individual items and analysis and indicated that items 2 and 16 were 'mediocre' (below 0.6) (Kaiser 1974). Item 16 "The best therapy sessions are when the speech & language therapist works with the child and parent alone" was also potentially ambiguous as it could be construed as a positive statement for those participants whose child received individual intervention and negative if they had only received group intervention. The KMO for the analysis of the 18 remaining items was acceptable (0.86). Bartlett's test of sphericity, $\chi^2 (153) = 1558.2$, $p < .001$, indicated that correlations between items were sufficiently large for factor analysis.

An initial analysis was run to obtain eigenvalues for each factor in the data. Four components had eigenvalues over Kaiser's criterion of 1 and in combination explained 66.6% of the variance. The scree plot showed an inflexion that would also justify retaining four factors. Table 9-8 shows the factor loadings after rotation for all items. Where items loaded onto more than one factor, the highest loading item was included with the exception of item 13. On face value this item appeared more suitable for inclusion in Factor 4, Therapist support. Of the four factors, all appeared coherent with factor one representing initial experience of SLT, factor two representing satisfaction with SLT, factor three: parental role in treatment and factor four: therapist support. All factors and also the total scale showed acceptable internal reliability (Cronbach's α pre 0.77 -.92).

Table 9-8 Structure Matrix: CSPQ

Item	Consumer Satisfaction Parent Questionnaire (CSPQ)	Factor**			
		1	2	3	4
1	I was satisfied with the referral process.	.47			
3	My child was seen for assessment within a reasonable period of time	.47			
4	I was satisfied with the explanation of the assessment findings	.99	.51		
5	I understood the relationship between the assessment findings and my child's therapy goals.	.79	.53	.53	
6	I understood my role in providing a home therapy program to my child.			.63	
7	It is important for parents to work with their child in a SLT program			.85	
8	I was directly involved in my child's therapy program.		.41	.77	-.44
9	Parent participation in the therapy program increases the chances of a child's success.			.75	
10	I received adequate help from the speech & language therapist in providing the home program.	.47	.68		-.82
11	I was provided with clear therapy goals and objectives for the home program.	.45	.67	.43	-.82
12	The speech & language therapist demonstrated the activities to show me what I could do at home.	.43	.55	.45	-.62
13	I was helped to find suitable therapy materials at home.	.40	.60		-.46
14	I was provided with a sufficient number of therapy sessions during the intervention program.		.66		
15	Appointments during therapy were suitably spaced.		.49		
17	I was satisfied with my child's progress during therapy	.59	.80	.47	-.47
18	I believe my child's speech & language improved as a result of the therapy.	.50	.73		
19	Pre-school SLT services were adequate.	.47	.87		
20	Considering everything, I was satisfied with the SLT service provided.	.67	.88		

****Items in BOLD included in factor**

FACTORS: 1: initial experience SLT 2: satisfaction SLT 3: parent role 4: therapist support

9.2.2 Internal Consistency of Measures

A minimum Cronbach alpha's of .7 was considered acceptable as it would explain approximately 50% of the variance in the true score explained by a scale. Less than this would indicate that correlations with other variables may be attenuated (Nunnally et al 1967).

9.2.2.1 Baseline Measures

Cronbach's Alpha for the baseline measure can be found in table 9-9.

IPQR-SLCN: The language difficulties and total symptom identity subscales showed good levels of internal consistency ($\alpha=.75$, $.76$). The internal consistency for Externalising symptoms and other behaviours were questionable ($\alpha= .68$, $.63$) and the internal consistency of final subscale (ASD phenotype) was poor ($\alpha=.41$). All subscales of the IPQR-SLCN views scale demonstrated at least good levels of internal consistency ($\alpha= .72$ to $.90$) with the exception of the control-child subscale and treatment control which were questionable ($\alpha= .64$, $.67$). With the exception of treatment control (child-control was novel to the present study) these levels are consistent with the psychometric evaluation of the original IPQ-R (with reported $\alpha=.79$ to $.89$) (Moss-Morris et al 2002). All domains of the cause scale demonstrated at least good levels of internal consistency ($\alpha= .75$ to $.82$) except the child-related subscale, which was questionable ($\alpha= .61$).

FLQ: Following factor analysis all domains and the total demonstrated at least good levels of internal consistency ($\alpha= .70$ to $.90$).

SEPTI: In the current study the majority of the subscales showed good levels of reliability (emotional availability $\alpha=.78$, play $\alpha=.84$, teach $\alpha=.82$, instrumental care $\alpha=.81$) with the total scale showing excellent internal consistency (46 items, $\alpha= .92$). The reliability of the nurturance subscales was improved with the deletion of item 13 ("I find it very distressing when my child isn't in a good mood") (6 items $\alpha= .80$). This was also true of the discipline scale when item 20 was removed ("When my child tests the limits that I have set up I find myself becoming extremely discouraged"), resulting in a Cronbach's α of $.72$ (6 items). With both these items removed the overall reliability of the scale showed a small improvement (44 items $\alpha= .93$). These reliability figures are at least consistent with, or an improvement on, previously reported alphas for the scales (e.g. Coleman & Karraker, 2003 ($\alpha=.60$ to $.92$), Whittaker & Cowley, 2012 ($\alpha=.61$ to $.87$)).

SE-SLTR: In both the development phase and in this study this measure demonstrated satisfactory reliability ($\alpha = .90$ and $.83$ respectively).

PETS: In the present research reliability was generally improved in comparison with the original measure. Acceptable reliability was shown for the full scale and for the credibility component ($\alpha = .82, .71$). Questionable reliability was achieved for child improvement ($\alpha = .63$) and also for parent involvement ($\alpha = .63$, with item 5 removed). The removal of the single item did not affect the overall internal consistency for the final 19 item scale.

FOCUS: In the present study the scale was highly reliable ($\alpha = .94$) and comparable to the published measure ($\alpha = .96$) (Thomas-Stonell et al., 2010; Thomas-Stonell et al., 2013).

Table 9-9 Summary of Cronbach's Alpha for baseline measures (*rated as good >.7)

	N Items	Min & Max score	Cronbach's α
IPQRSLCN identity			
Externalising behaviours	4	0 - 4	.68
Language difficulties	3	0 - 3	.75*
Other behaviours	3	0 - 3	.63
ASD social communication phenotype	3	0 - 3	.41
Total Identity Scale (All items)	31	0 - 31	.76*
Total symptoms related to SLCN	31	0 - 31	n/a
IPQRSLCN Views			
Timeline acute/chronic	6	6 - 30	.87*
Timeline cyclical	4	4 - 20	.81*
Consequences-total	9	9- 45	.90*
Consequences-child	3	3 - 15	.75*
Consequences-parent	3	3 - 15	.77*
Personal control	12	12 - 60	.74*
Control-child	6	6 - 30	.64
Control-parent	6	6 - 30	.72*
Treatment control	5	5 - 25	.67
Illness coherence	5	5 - 25	.85*
Emotional representations	5	5 - 25	.86*
IPQRSLCN Cause			
External causes	6	7 - 35	.80*
Self-blame	3	3 - 15	.75*
Early medical experiences	5	5 - 25	.82*
Child related	3	3 - 15	.61
FLQ			
Child communication	3	3 - 15	.82*
Child social competence	6	6 - 30	.80*
Impact on Family Life	8	8 - 40	.84*
Confidence in helping child	7	7 - 35	.82*
Treatment Experience	4	4 - 20	.70*
Total FLQ	28	28 - 140	.90*
SEPTI-TS			
Emotional Availability	7	7-42	.78*
Nurturance (1 item removed)	7	7-42	.80*
Discipline (1 item removed)	6	6-36	.72*
Play	7	7-42	.84*
Teach	9	9-63	.82*
Instrumental Care	8	8-56	.81*
Total Parenting Self-efficacy	46	46-276	.92*
Total Parenting Self-efficacy (2 items deleted)	44	44-264	.93*
SE-SLTR	9	9-63	.83*
PETS			
Credibility	10	10-50	.71*
Child Improvement	6	6-30	.63
Parent Involvement (1 item deleted)	4	3-15	.63
Total Expectancies (1 item deleted)	19	19-95	.82*
FOCUS Baseline	50	5-350	.94*

9.2.2.2 Follow up measures

Table 9-10 provides a summary of the internal consistency of the measures using Cronbach Alpha.

Table 9-10 Cronbach's Alpha for follow-up measures

	N Items	Min & Max score	Cronbach's α
FOCUS Baseline	50	5--350	.90*
WAI			
Task alliance	4	7 - 28	.92*
Bond alliance	5	7 - 35	.90*
Goal alliance	4	7 - 28	.75*
General Alliance	13	7 - 91	.94*
BTPS			
Competing Activities/Life Stressors	19	19 - 95	.77*
Relevance of Treatment	8	8 - 40	.74*
Relationship with SLT	6	6 - 30	.75*
Treatment issues	8	8 - 40	.68
Total BTPS Score	41	41 - 205	.87*
CSPQ			
Initial experience of SLT	4	4 - 20	.77*
Satisfaction	6	6 - 30	.88*
Parental Role in Treatment	4	4 - 20	.84*
Therapist Support	4	4 - 20	.85*
Total CSPQ -SLT	18	18 - 90	.92*

*Rated as good >.7

FOCUS: In the present study the scale was also highly reliable at follow up ($\alpha = .90$) and again comparable to the published measure ($\alpha = .96$) (Thomas-Stonell et al., 2010; Thomas-Stonell et al., 2013).

WAI-S: The reliability of goal alliance was lower in this study in comparison to the original ($\alpha=.90$ to $.98$) (Tracey & Kokotovic, 1989) but remained satisfactory ($\alpha=.75$); all other subscales were directly comparable and showing adequate levels of internal consistency.

BTPS: Internal reliability for each subscale was acceptable (Cronbach's $\alpha=.74$ -.87) with the exception of the treatment issues domain which was questionable ($\alpha=.68$). Cronbach's alpha's

for the subscales were not reported in the original version so comparisons are not possible (Kazdin et al., 1997).

CSPQ: All four subscales and the total measure demonstrated satisfactory internal consistency overall ($\alpha = .77$ to $.92$). The internal consistency for the overall scale ($\alpha = .92$) was comparable to the pilot study ($\alpha = .93$).

9.3 Descriptive Statistics

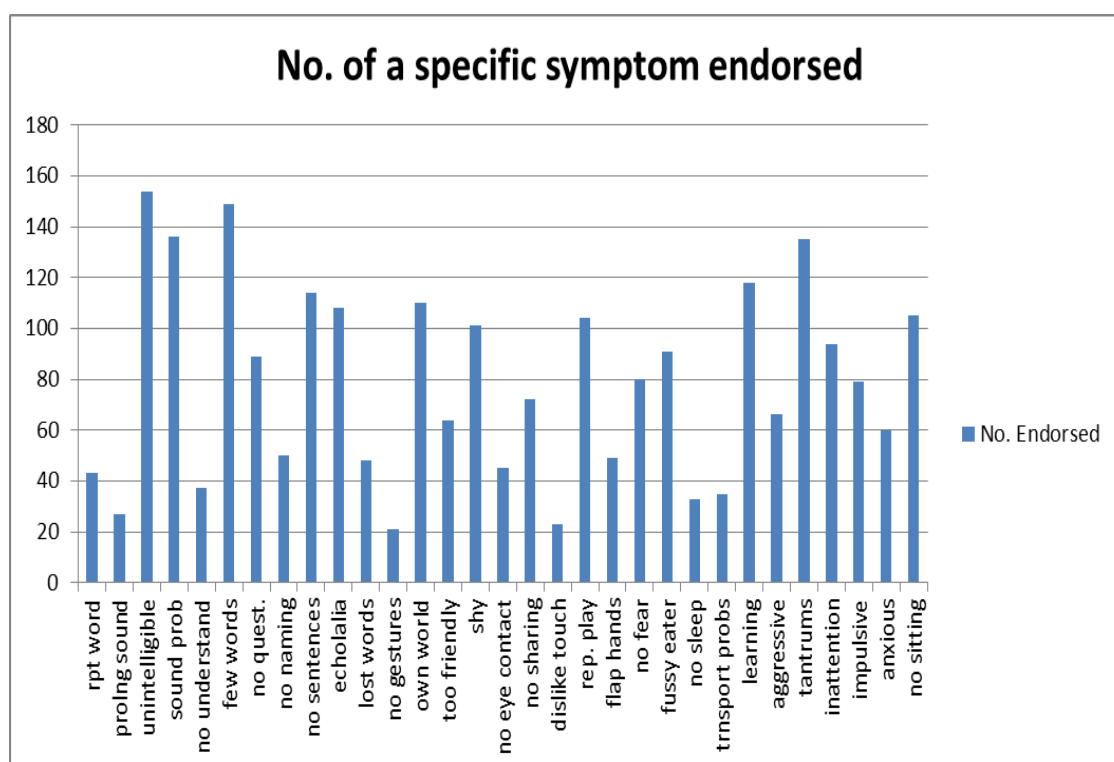
9.3.1 Parent Rated measures

9.3.1.1 Baseline Measures

Table 9-13 provides the descriptive statistics for all measures at baseline including mean, standard deviation, range and measure of skewness. A brief summary of the general tendency of the responses of whole group is provided.

IPQR SLCN-Identity: Parents identified a wide range symptoms (1-26) but with an average of twelve and they considered on average, four to be unrelated to SLCN (0-17). Symptoms endorsed included those related to the domains of language difficulties, externalising behaviours and those found in children with Autism Spectrum disorders (ASD). There were fewer endorsements of other behaviours ($\bar{X} = .59$) which included difficulties with sleep and transport. All symptoms were endorsed by at least twenty parents suggesting that the symptoms were relevant to their experience (table 9-11).

Table 9-11 IPQR-SLCN Identity: number of symptoms endorsed



The symptoms endorsed most frequently (>100 identified) can be seen in table 9-12, with the most common being item 3 (doesn't speak clearly/difficult to understand) followed by item 6 (reduced vocabulary/has few words) and item 27 (tantrums).

Table 9-12 Child symptoms identified by parents >100 endorsements

IPQR-Id no.	Description	No. of endorsements
3	Doesn't speak clearly/is difficult to understand	154
4	Doesn't say speech sounds properly	136
6	Reduced vocabulary/has few words	149
9	Doesn't put words together into sentences	114
10	Repeats what is said (when not asked to)	108
13	Is in his/her own world	110
15	Is shy	101
19	Plays with objects repetitively or intensely	104
25	Is behind in his/her learning	118
27	Tantrums	135
31	Doesn't sit still	105

For each measure, the overall mean for a domain (table 9-13) was divided by the number of items in the subscale to allow a direct comparison with the original scales to support interpretation.

IPQRSCLN-Views: The overall tendency was for parents to rate their child's SLCN to be of shorter duration (\bar{X} =2.37), not cyclical (\bar{X} =2.53) and to have few consequences (total \bar{X} =2.68) (slightly higher for their children (\bar{X} =2.83) than themselves (\bar{X} =2.63)). Parents generally agreed that they, and their child, were in control (Total \bar{X} =3.45). The overall tendency for participants was to believe that treatment could control their child's SLCN (\bar{X} =4.80). Participants considered themselves to have a coherent understanding of their child's problem (\bar{X} =3.64). The overall tendency was for parents to agree that they experienced negative emotions in response to their child's SLCN (\bar{X} =3.52).

IPQR-SLCN Cause: Parents generally endorsed multiple causes, with only one parent indicating none (\bar{X} =6.42, range 0-29). Overall parents attributed external causes over self-blame, early medical experiences or child-related causes.

SEPTI-TS: Parents in the study demonstrated an overall tendency towards being confident in their parenting skills, both overall (\bar{X} =4.91) and within each of the domains (\bar{X} =4.63 to 5.69). The trend was for parents to be most confident in nurturing their child (\bar{X} =5.69). They were least confident in teaching their child (\bar{X} =4.64) and in providing instrumental care (\bar{X} =4.63).

SE-SLTR: Parents tended to rate themselves as being confident in their ability to carry out SLT recommendations when faced with certain demands (\bar{X} =6.41).

PETS: Parents were overall positive in their expectancies of SLT treatment across all domains (\bar{X} =3.15 to 4.05) and the total (\bar{X} =3.96). The lowest expectations were for parental involvement (\bar{X} =3.15), suggesting some uncertainty in their role, and the highest for child improvement (\bar{X} =4.05).

FOCUS: The tendency was for most parents to rate their child as being somewhat towards the centre of the overall scale (\bar{X} =3.75).

Table 9-13 Descriptive statistics for baseline measures and subscales

Scale (n of items)	N Valid	Missing	Mean (SD)	Range	z-skew
IPQR-SLCN Identity					
Externalising behaviours (4)	199	0	1.73 (1.4)	0-4	1.32*
Language difficulties (3)	199	0	1.27 (1.18)	0-3	1.51*
Other behaviours (3)	199	0	0.59 (0.90)	0-3	8.46
ASD social communication phenotype (3)	199	0	1.81 (0.98)	0-4	-1.37*
Total Identity Scale score (31)	199	0	12.3 (4.91)	1-26	1.35*
Total symptoms related to SLCN	199	0	8.1 (5.11)	0-23	5.23
IPQR-SLCN Views					
Timeline (6)	199	0	14.2 (4.38)	6-25	1.82*
Consequences Total (9)	199	0	24.1 (7.16)	9-42	0.25*
Consequences Child (3)	199	0	8.5 (2.91)	3-15	0.14*
Consequences parent (3)	199	0	7.9 (2.59)	3-14	-0.06*
Personal Control Total (12)	199	0	41.4 (5.69)	24-56	-0.63*
Control Child (6)	199	0	20.9 (3.92)	6-30	-1.93*
Control Parent (6)	199	0	20.5 (4.19)	10-30	0.08*
Treatment Control (5)	199	0	19.2 (2.56)	9-25	-2.70*
Illness Coherence (5)	199	0	18.2 (3.68)	6-25	-2.52*
Timeline Cyclical (4)	199	0	10.1 (3.37)	4-19	1.89*
Emotional representations (5)	199	0	17.6 (5.04)	6-29	-1.56*
IPQR-SLCN Cause					
External (6)	198	1	10.7 (3.23)	6-18	-0.77*
Self-blame (3)	198	1	6.52 (2.45)	3-14	3.46
Early medically experience (5)	198	1	8.87 (3.04)	5-20	3.21
Child related (3)	198	1	7.07 (2.28)	3-13	0.53*
Total no. causes endorsed	198	1	6.42 (3.49)	0-29	10.9
FLQ: Baseline					
Child communication (3)	199	0	6.30 (2.93)	3-15	5.60
Child social competence (6)	199	0	14.1 (4.65)	6-28	2.61*
Impact on Family Life (8)	199	0	17.5 (6.19)	8-35	3.38
Confidence in helping child (7)	199	0	15.6 (4.82)	7-30	0.93*
Treatment experience (4)	199	0	8.03 (3.02)	4-17	2.93*
Total SLCN FLQ (28)	199	0	61.5 (15.4)	29-103	2.02*
SEPTI-TS					
Emotional Availability (7)	199	0	35.6 (3.96)	19-42	-4.31
Nurturance (7)	199	0	39.8 (3.49)	28-48	0.13*
Discipline(6)	199	0	28.4 (4.63)	15-41	-2.29*
Play (7)	199	0	33.0 (5.08)	16-42	-5.95
Teach (9)	199	0	41.8 (6.04)	23-54	-3.87
Instrumental Care (8)	199	0	37.1 (5.83)	13-48	-5.45
Total Parenting Self-efficacy (44)	199	0	215.8 (21.6)	127-269	-3.60
SE- SLT (9)	199	0	44.9 (8.19)	12-63	-3.36
PETS					
Credibility (10)	199	0	38.9 (4.20)	24-47	-2.71*
Child Improvement (6)	199	0	24.3 (3.72)	16-31	-0.71*
Parent Involvement (4)	199	0	12.6 (1.73)	7-15	-2.12*
Total Expectancies (20)	199	0	75.4 (7.87)	54-91	-1.47*
FOCUS (50)	199	0	187.6 (57.6)	70-317	1.15*

*distribution assessed as normal

FLQ Baseline: The general tendency was for parents to rate their child and family as functioning adequately across all domains and the total (\bar{X} =2.10 to 2.35).

9.3.1.2 Follow up measures

Table 9-14 provides the descriptive statistics for follow up measures. A brief summary of the general tendency of the whole sample is provided.

For each measure, the overall mean for a domain (table x) was divided by the number of items in a subscale to allow a direct comparison with the original scales to support interpretation.

FLQ Treatment Experience (Original scale rated as 1-5): At follow up the tendency was for parents to give positive views on their experience of treatment ($\bar{X}=1.6$)

WAI (Original scale rated as 1-7): The overall trend was for participants to rate the therapeutic alliance as positive ($\bar{X}=5.72$). The lowest rating was given to 'bond' representing the relationship with the SLTherapist ($\bar{X}=4.5$) and the highest to 'task' ($\bar{X}=5.8$) representing agreement with therapy activities.

MATIF Recommendations: Across the whole sample 1283 recommendations were made with an average of 8-9 per child. The overall tendency was for parents to consider the majority to be important (88%). Recommendations were classed into one of four categories (chapter 7, section 7.3.3.1); three types emerged: A: Active self-help, referring to the majority of the recommendations (n= 1110, 86.5%) and D: SLT services which specifically related to a single recommendation repeated for all participants "to attend SLT appointments offered" (n=140, 10.9%). Category B: consult with other professionals also occurred, but with the lowest frequency occurring on 33 (2.6%) occasions.

Table 9-14 Descriptive statistics for follow-up measures and subscales

	N		Mean (SD)	Range	z-skew
	Valid	Missing			
FLQ (Follow-up)					
Treatment Experience (4)	148	51	8.0 (3.30)	4-17	3.28
WAI					
Task alliance (4)	148	51	23.2 (5.34)	4-28	-6.48
Bond alliance (5)	148	51	22.5 (4.84)	6-28	-4.16
Goal alliance (4)	148	51	23.0 (4.69)	4-28	-5.67
WAI Total (13)	148	51	74.3 (15.0)	17-91	-5.83
BTPS					
Competing Activities/Life Stressors (19)	148	51	23.9 (5.26)	19-48	8.68
Relevance of Treatment (8)	148	51	9.91 (3.27)	7-27	12.19
Relationship SLT (6)	148	51	6.67 (1.92)	6-21	24.94
Treatment issues (8)	148	51	9.78 (2.83)	8-26	14.85
Total BTPS Score (41)	148	51	50.3 (10.1)	41-98	9.64
Total No. of barriers	148	51	5.68 (5.07)	0-23	6.07
MATIF					
Number of recommendations made	148	51	8.7 (2.85)	1-15	-0.25*
Importance	147	52	87.7 (14.4)	21-100	-8.70
Degree of Improvement (parent)	140	59	3.98 (1.22)	1-5	-4.39
Degree of Improvement (education)	95	104	3.82 (1.34)	1-5	-3.50
CSPQ-SLT					
Initial experience of SLT (4)	148	51	16.3 (2.74)	7-20	-4.06
Satisfaction (6)	148	51	23.4 (4.60)	10-30	-4.02
Parental Role in Treatment (4)	148	51	18.0 (1.82)	11-20	-3.36
Therapist Support (4)	148	51	16.4 (2.95)	4-20	-7.51
Total CSPQ (18)	148	51	74.1 (10.0)	32-90	-4.04

*distribution assessed as normal

A random sample (10 cases) was examined to consider the potential to reclassify 'active self-help' into smaller categories, which would allow the effects of barrier type to be explored. The sample contained 89 recommendations and a thematic analysis revealed seven types of recommendations (see table 9-15). A recommendation was identified as a 'New technique' rather than 'Activity' when the method being recommended was judged to be outside a person's typical communication and interaction repertoire. For example, although 'special time' might be considered a new technique, the skills employed within it are not. The differences in the mean adherence ratings for the different types of recommendation suggest

that parents may respond differently depending on the type of the recommendations. Further analysis of the recommendations was not completed in this study due to the large sample size.

Table 9-15 Re-classification of 'Active self-help' and mean adherence ratings

Classification	n	M
External support e.g. to use the 'pees and poos clinic' for toileting	5	3.2
Parent take action e.g. [during special time] reduce distractions, turn off the TV	3	4.7
New technique e.g. to use the 'wait' strategy as advised	9	4.4
Activity e.g. spend 5-10 minutes playing with him every day: 'special time'	11	3.9
Reference e.g. to read the recommended self-help book	3	3.6
Model e.g. to model transport and verb vocabulary especially during travel activities	7	4.7
Parent change own behaviour e.g. give him time to talk, if you ask a question wait an extra couple of seconds	38	4.2

Parents were also asked to rate any change in their children's skills. When asked if their child's skills have changed or not, only five parents stated that they had not. Where skills had changed most parents reported positive improvements with the mean and mode both being close to rating of four out of five. Only one parent indicated that their child's skills had worsened. Ninety five parents felt able to comment on the nursery's view of their child's progress lack of response was mainly due to their child not being in education, or they didn't know. No parent indicated that their child's nursery thought their child's skills had worsened.

MATIF Barriers to Specific Recommendations: Parents were asked to select all barriers that were relevant to them for a specific recommendations (total barriers =7) and given an opportunity to describe any other barriers not previously specified ('other'). Table 9-16 summarises the number of times each barrier was endorsed across the whole sample. The most frequently cited barriers were time, forgot to do it and my child didn't want to do it.

Table 9-16 Frequency of responses to barriers to following recommendations

CODE	Description	No. endorsed
1.	Didn't think it would help	108
2.	No longer a problem	36
3.	Resources not available	42
4.	Transportation	9
5.	Time	383
6.	Forgot to do it	337
7.	My child didn't want to do it	249

A small sample of parents free text responses to the 'other' barrier category was taken from their first recommendation and the content categorised, revealing a further seven types of barrier (table 9-17). Of these 'sickness' and 'other commitments' were the most frequently endorsed.

Table 9-17 Additional barrier codes obtained from 'free' responses for a single recommendation

CODE	Description	No. endorsed
1.	Sibling issues	5
2.	Family issues (Bereavement/ childcare)	2
3.	Sickness (child/parent unwell)	13
4.	Dissatisfaction with therapy (group & therapy style)	4
5.	Communication (no letter/moved)	3
6.	Other commitments (holiday/work/religious)	11
7.	SLT advised against	2

Due to the large sample size, the influence of particular barriers on adherence to a recommendation was not analysed further.

CSPQ: Overall participants appeared satisfied with their experience of SLT (\bar{X} =4.12). Within the sub-domains, the lowest mean was found in domain focusing on satisfaction generally (\bar{X} =3.90) and the highest relating to satisfaction with parental role in treatment (\bar{X} =4.50).

9.3.2 Primary Outcome measures

AIM:

1. To identify levels of attendance at SLT sessions and adherence to individual treatment recommendations in two inner London Boroughs.

Descriptive statistics for the three main outcome variables are presented in table 9-18. Participants missed on average two appointments over the course of the study but with a range of zero to eight. The overall degree of adherence (Dadh) was 74.1%. For child outcome at follow up, the tendency was for most parents to rate their child as being somewhat towards the middle to high end of the overall scale (\bar{X} =4.52). Change in baseline FOCUS scores was normally distributed and on average 40.9 (range -63-142). Change was clinically meaningful for 70.7% of the sample (MCID=16). A small proportion of children (13%) had lower scores at follow-up than at baseline, with changes clinically meaningful for 5%.

Table 9-18 Descriptive statistics for main outcome variables

	N Valid	Missing	Mean (SD)	Range	z-skew
ATTENDANCE:					
Missed appointments (DNA)	199	0	1.96 (1.90)	0-8	7.26
ADHERENCE:					
Dadh (MATIF)	148	51	74.1 (17.2)	0-100	-5.24
CHILD OUTCOME:					
FOCUS Follow-up Score	148	51	226.0 (63.2)	83-343	-1.69*
FOCUS Change	148	51	40.9 (37.5)	-63-142	1.25*

* normally distributed

9.4 Inferential Statistics

AIMS:

1. To determine the extent to which parental factors such as beliefs (illness perceptions, self-efficacy, expectations of treatment), experience of treatment (therapeutic alliance, satisfaction) which child characteristics and personal circumstances (family functioning, SES, practical barriers) relate to:
 - a) Attendance
 - b) Adherence to home-based recommendations
 - c) Child outcomes
2. To identify whether attendance and adherence are related to child outcome.

As per the study aims, independent variables were classified into four domains: 'Parents personal circumstances', 'parent beliefs', 'child characteristics' and 'Parents experience of treatment'(p.230). 'Parent beliefs' was subdivided into those relating to the child's problem and those relating to parents self-confidence. Relevant data from all but 'child characteristics' were collected at both baseline and follow up. For the purpose of modelling the data only those variables with effect sizes greater than .20 were included in the regression models. Using effect sizes has the potential to avoid any confounding factors related to sample size as might be observed when using p values alone (Sullivan & Feinn, 2012).

9.4.1 Predicting Non-attendance

AIMS:

1. To determine the extent to which **parental factors** such as beliefs (illness perceptions, self-efficacy, expectations of treatment), experience of treatment (therapeutic alliance, satisfaction) and personal circumstances (family functioning, SES, practical barriers) relate to non-attendance.
2. To determine the extent to which **child characteristics** relate to adherence to non-attendance.

Hypothesis:

- Predictors of non-attendance will include parental factors (personal circumstances, beliefs: child problem, self-efficacy; experience of treatment) and child characteristics.

In order to test this hypothesis correlations between all factors within the four domains and non-attendance (DNA) were examined. Those with effect sizes greater than .2 (table 9-19) were subsequently included in regression analyses with each domain treated separately before being considered as a single model predicting DNA.

In the 'parents personal circumstances' domain, the included variables were maternal age, maternal education level and ethnicity. At follow-up the variables BTPS competing stressor and FLQ: Impact on Family Life (post) were included. In 'Parent beliefs child problem' the following subscales of the IPQRSLCN were included: timeline cyclical and early medical causes. The only included variable within parental self-efficacy beliefs domain was instrumental care (SEPTI-TS). In the child features area, the single variable meeting an acceptable effect size was total symptoms reported (IPQRSLCN identity scale). The final area was parent's experience of treatment, measured at follow up; no variable met the pre-defined criteria for inclusion in the model. Non-significant correlations are reported in appendix 9.1.

Table 9-19 Spearman's Rho correlations between DNA and statistically significant predictor variables

Variable	N	Correlation	Sig. (2-tailed)
Parent Personal circumstances			
Age of mother	193	-.21	.003
Maternal Final Education level	198	-.29	.000
Ethnicity	198	-.20	.010
BTPS Competing Activities/Life Stressors	148	.22	.007
FLQPost Family Impact	148	.25	.002
Parent Beliefs			
Illness perceptions			
IPQRSLCN Timeline Cyclical	199	.27	.000
IPQRSLCN external cause	198	.17	.014
IPQRSLCN self-blame cause	198	.15	.033
IPQRSLCN early medical cause	198	.25	.000
Self-efficacy			
SEPTI-TS teach	199	-.18	.009
SEPTI-TS Instrumental care	199	-.20	.006
Child features			
IPQRSLCN Externalising behaviour Symptoms	199	.17	.017
IPQRSLCN Social Communication Symptoms	199	.17	.019
IPQRSLCN Total Number of symptoms reported	199	.22	.002
IPQRSLCN Number symptoms related to SLCN	199	.17	.019
Parents treatment experience			
FLQPost Treatment Experience	148	.18	.029
WAI Goal alliance	148	-.18	.026

Goodness of fit indicators were compared; the best fitting model was negative binomial with the negative binomial parameter estimated, final model fit statistics are provided in table 9-20. A negative binomial regression was therefore conducted for each of the three areas including the two parent beliefs sub sections. For each area, variables that were significantly correlated with DNA were entered into the model as independent variables. The dependant variable was DNA with total number of appointments offered as the offset variable (accounting for the variation in the number offered i.e. exposure); the results are reported in table 9-20.

Table 9-20 Summary of Negative Binomial Regressions for individual domains predicting missed appointments

Predictor Variable	Negative Binomial			
	B	SE B	e ^b	p
A. Parent Personal Circumstances (baseline) (N=193)				
Maternal Age	-.033	.011	.968	.002**
Maternal Final Education level	-.18	.044	.836	.000**
Ethnicity	-.23	.13	.795	.074
(Scale)	1 ^a			
(Negative binomial)	.17	.072		
Parent Personal Circumstances Model Baseline: χ^2 (2) = 30.9 p<.001**				
Model Fit Statistics: Log Likelihood -32.8, AIC 665.6, BIC 681.9				
Parent Personal Circumstances (follow up) (N=148)				
FLQ (post) Family Impact	.039	.014	1.039	.004**
BTPS (post) Competing Activities/Life Stressors	.017	.014	1.017	.21
(Scale)	1 ^a			
(Negative binomial)	.24	.10		
Parent Personal Circumstances Model Follow up: χ^2 (2) = 12.6 p=0.002				
Model Fit Statistics: Log Likelihood -247.1, AIC 502.1, BIC 514.1				
B. Parent Beliefs: child problem (N=198)				
IPQRSLCN Timeline Cyclical	.053	.018	1.054	.004**
IPQRSLCN Early medical cause	.060	.020	1.062	.003**
(Scale)	1 ^a			
(Negative binomial)	.21	.076		
Parent Beliefs: child problem Model: χ^2 (2) = 19.15 p<0.001**				
Model Fit Statistics: Log Likelihood -344.1, AIC 696.2, BIC 696.4				
B1. Parent Beliefs: self-efficacy (N=199)				
SEPTI-TS Instrumental care	-.028	.001	0.972	.005**
(Scale)	1 ^a			
(Negative binomial)	.25	.083		
Parent Beliefs: self-efficacy Model: χ^2 (2) = 7.57 p<0.01**				
Model Fit Statistics: Log Likelihood -351.3, AIC 708.7, BIC 718.5				
C. Child features (N=199)				
IPQRSLCN Total symptoms reported	.033	.013	1.034	.011**
(Scale)	1 ^a			
(Negative binomial)	.273	.083		
Child features Model: χ^2 (1) = 6.43 p=0.01**				
Model Fit Statistics: Log Likelihood -351.9, AIC 709.8, BIC 709.8				
a. Fixed at the displayed value. *p<.05 **p<.01				

A. Parent Personal circumstances: *Baseline Model:* Maternal Age, Maternal Final Education level and ethnicity.

The overall model was significant ($p < .001$). The contribution of maternal age to the model was significant ($p = .003$) with the rate ratio $e^b = 0.97$. Thus for every one- year increase in the age of mothers, non-attendance decreased by 3.2% (holding maternal education level constant). The contribution to the overall model for the final education level of mothers was also significant ($p < .001$), with a rate ratio of 0.838, therefore for each point increase in final education level there was a 16.4% decrease in non-attendance. Ethnicity (white/BME) was non-significant in the model.

Follow up model: FLQ (post): Family Impact and BTPS (post): Competing Activities/Life Stressors.

The overall model was significant ($p = .002$). The contribution of Family Impact to the model was significant ($p = .004$) with the rate ratio $e^b = 1.039$. Thus for every one point increase in family impact, non-attendance increased by 3.9% (holding BTPS factor constant). The BTPS factor did not reach significance.

B. Parent beliefs (child problem): Model: IPQRSLCN timeline cyclical and IPQRSLCN Cause: early medical domain.

The overall model was significant ($p < .001$). The contribution of the timeline cyclical variable was significant ($p = .004$) therefore, and holding other variables constant, each single point increase in belief in the child's problem being cyclical in nature resulted in a 5.4% increase in the number of appointments missed. The variable early medical cause was also significant ($p = .003$) indicating that a single-point increase in the belief of such a cause, holding all other predictors constant, led to a 6.2% increase in missed appointments.

B1. Parent beliefs (self-efficacy): Model: SEPTI-TS Instrumental care.

The overall model was significant ($p < .01$) and indicated that a single point increase in a parents confidence in providing instrumental care to their child led to a 2.8% increase in missed appointments.

C. Child features: Model: IPQRSLCN identity scale: total symptoms reported.

The overall model was significant ($p=0.01$). The rate ratio indicated that for each additional symptom reported a corresponding 3.4% rise in attendance was observed.

Overall Combined model A-C.

To assess the effects of all variables in models A-C a further regression was conducted. All factors were entered in five blocks using an estimated negative binomial parameter. Model fit statistics (Log Likelihood, AIC and BIC criteria) were compared at each step (table 9-21). The model improved at steps two and three, as evidenced by the reduction in the model fit statistics. At step four, the Log Likelihood reduced significantly ($p=.04$) as did the AIC criteria; however, the BIC increased suggesting that the gain in fit, balanced against model complexity, was negligible. In the final step the change in log likelihood was non-significant ($p=.317$). The model selected as best fit in the context of an explorative study, was the model represented at step four.

The final model (4) was significant ($p<.001$) (table 9-22) and using McFadden's pseudo R^2 the overall model explained 40% of the variance in attendance. Holding all other variables constant the rate ratios indicated that for each point increase in maternal final education level the number of sessions missed decreased by 14.2%; for each point increase (equivalent to a year) in the age of the mother the number of sessions missed decreased by 2.5%; for each point increase in a belief in a medical cause sessions missed increased by 5.5% and for each point increase in parents confidence in providing instrumental care the number of sessions missed decreased by 2.2%. The effects of ethnic group, family impact, timeline cyclical and competing activities/life stressors were not significant.

In summary, better attendance was observed in mothers who achieved higher levels of education, who were older, who were less likely to endorse an early medical experience as a cause of their child's SLCN and who were more confident in providing instrumental care for their child.

Table 9-21 Comparison of Negative Binomial & Poisson Stepwise Regression Models (incorporating all variables): model fit statistics

Model (offset = no. appointments offered)	N	df	Log Likelihood	AIC	BIC	Pseudo R ²
1: (DNA), ethnic group, age of mother, maternal final education level,	193	3	-327.8	665.6	681.9	.11
2. (DNA), ethnic group, age of mother, maternal final education level, FLQ (post): Family Impact and BTPS (post): Competing Activities/Life Stressors	144	5	-229.9	473.9	494.7	.38
3. (DNA), ethnic group, age of mother, maternal final education level, FLQ (post): Family Impact and BTPS (post): Competing Activities/Life Stressors IPQRSLCN timeline cyclical, IPQRSLCN early medical cause	143	7	-224.6	467.2	493.9	.39
4: (DNA), ethnic group, age of mother, maternal final education level, FLQ (post): Family Impact and BTPS (post): Competing Activities/Life Stressors IPQRSLCN timeline cyclical, IPQRSLCN early medical cause, SEPTI-TS Instrumental care.	143	8	-222.6	465.2	494.8	.40
5: (DNA), ethnic group, age of mother, maternal final education level, FLQ (post): Family Impact and BTPS (post): Competing Activities/Life Stressors, IPQRSLCN timeline cyclical, IPQRSLCN early medical cause, SEPTI-TS Instrumental care, IPQRSLCN total symptoms reported	143	9	-222.1	466.2	498.8	.40

Table 9-22 Full model: Negative Binomial Regression Predicting missed appointments

Predictor Variable N=143	Negative Binomial			p	Confidence Intervals
	B	SE B	e ^b		
Ethnic Group (BME)	.178	.14	1.195	.20	0.08-1.71
Maternal Final Education level	-.153	.050	0.858	.002**	0.78-0.95
Age of Mother	-.025	.011	0.975	.028*	0.95-1.00
FLQ (post): Family Impact	.007	.013	1.007	.56	0.98-1.03
BTPS (post): Competing	.019	.012	1.019	.10	1.00-1.04
IPQRSLCN timeline cyclical	.018	.023	1.018	.45	0.97-1.07
IPQRSLCN early medical cause	.054	.022	1.055	.013*	1.01-1.10
SEPTI-TS Instrumental care	-.022	.010	0.978	.034*	0.96-0.99
(Scale)	1 ^a				
Full Model: $\chi^2(8) = 46.5$ $p < .001$ ** a. Fixed at the displayed value. * $p < .05$ ** $p < .01$					

9.4.2 Predicting Degree of Adherence (DAdh)

AIMS:

1. To determine the extent to which **parental factors** such as beliefs (illness perceptions, self-efficacy, expectations of treatment), experience of treatment (therapeutic alliance, satisfaction) and personal circumstances (family functioning, SES, practical barriers) relate to adherence to home-based recommendations
2. To determine the extent to which **child characteristics** relate to adherence to home-based recommendations

Hypothesis:

- Predictors of adherence to home-based recommendations will include parental factors (personal circumstances, beliefs: child problem, self-efficacy; experience of treatment) and child characteristics.

In order to test this hypothesis, correlations between all factors within the four domains DAdh were examined. Those with effect sizes greater than .20 (table 9-23) were subsequently included in regression analyses with each domain treated separately before being considered as a single model predicting DNA.

Relationships between DAdh and independent variables were examined using Spearman's rho. Significant relationships can be seen in table 9-23. Relationships are described relative to the four areas: 'parent beliefs' (child's problem/ parent self-efficacy), 'Parents personal circumstances', and 'Parents experience of treatment', the regression is then reported. DAdh was not related to any variables within the 'child characteristics' domain. A complete table of non-significant correlations is in appendix 9.2.

Table 9-23 Significant correlations between Dadh and predictor variables (bold items included in multiple regressions)

	N	Correlation	Sig. (2-tailed)
Parents' Personal Circumstances			
Total languages spoken	146	.23**	.006
BTPS Competing Activities/Life	148	-.31**	.000
FLQ Family impact	148	-.28**	.000
Parents' Beliefs (child Problem)			
IPQRSLCN Consequences total	148	-.16*	.047
IPQRSLCN Consequences Child	148	-.20*	.016
IPQRSLCN Emotional	148	-.18*	.026
IPQRSLCN Self-blame cause	147	-.23**	.006
Parents' Beliefs (self-efficacy)			
FLQ Parent confidence to help	148	-.49**	.000
SEPTI-TS Emotional availability	148	.36**	.000
SEPTI-TS Nurture	148	.32**	.000
SEPTI-TS Discipline	148	.35**	.000
SEPTI-TS play	148	.32**	.000
SEPTI-TS teach	148	.38**	.000
SEPTI-TS Instrumental care	148	.26**	.001
SEPTI-TS Total	148	.44**	.000
SE-SLTR	148	.38**	.000
Treatment Experience (baseline)			
FLQ Treatment Experience Domain	148	-.24**	.003
PETS expect child improvement	148	.30**	.000
PETS parent involvement	148	.24**	.004
PETS Total	148	.24**	.004
Treatment Experience (follow-up)			
WAI Task alliance	148	.31**	.000
WAI Bond Alliance	148	.39**	.000
WAI Goal alliance	148	.29**	.000
WAI Total	148	.38**	.000
Degree of importance of Rec.	147	.54**	.000
BTPS Relevance of treatment	148	-.18*	.029
BPTS Relationship with SLTherapist	148	-.18*	.029
BTPS Treatment Issues	148	-.25**	.002
Total No. of barriers	148	-.31**	.000
CSPQ first exp. SLT	148	.21**	.010
CSPQ Satisfaction	148	.32**	.000
CSPQ Parent Role	148	.29**	.000
CSPQ SLTherapist help	148	.31**	.000
CSPQ Total	148	.34**	.000

A. Parents beliefs Model: the following subscales of parents beliefs about their child's problem were significantly correlated with DAdh: IPQRSLCN Consequences Child ($r_s(147)=-.20$ $p=.02$), and IPQRSLCN self-blame cause ($r_s(146)=-.23$ $p=.006$). In the area of parents confidence in themselves, the following subscales were significantly correlated with DAdh: FLQ Parent confidence to help ($r_s(147)=-.49$ $p<.001$), SEPTI-TS Total ($r_s(147)=.44$ $p<.001$) and SE to follow recommendations total ($r_s(147)=.38$ $p<.001$). These were entered into the model with the largest correlation entered first and grouped according to self-efficacy beliefs and beliefs related to the child's problem.

This model was checked to ensure that all assumptions were met. The Durbin-Watson statistic confirmed the independence of the observations ($d= 1.963$) (an expected value of 2 indicates assumptions met, Field 2009). The scatter plot of standardised predicted value and residuals was indicative of homoscedasticity and of linearity (figure 9-1). There was no evidence of multicollinearity: the predictor variables were not substantially correlated ($r < .9$), the VIF collinearity statistics were well below 10 and the tolerance statistics are greater than 0.2. However, the K-S test was significant $D(147)=0.09$, $p=.009$ indicating that the residuals were not normally distributed. Case wise diagnostics identified five cases with residuals greater than 2 which were within expectations for a sample size of 148 (where 8 cases (5%) would have been expected to have values over 2) (Field 2009). As four cases had standardised residuals over 2.5 (two over 4), exceeding the expected 1% (Field 2009), all cases were investigated further. All Cooks distances were below 1, the centred leverage values were all within twice the size of the average leverage (0.095), and Mahalanobis Distance were acceptable given the sample size; but, as the co-variance ratios for all four were outside of the upper limits of acceptable values (range 0.148 to -0.952), these four cases were therefore excluded (cases 23, 45, 104, 197). With their removal, the residuals distribution was now normal, supported by the P-P plot and the non-significant K-S test $D(143)=0.04$, $p=.20$.

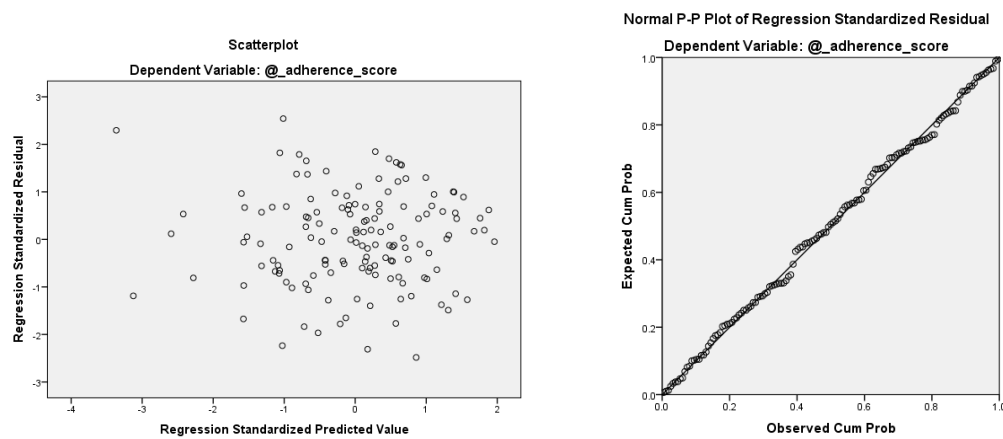


Figure 9-1 Scatterplot & PP Plot of standardised residuals: evidence of homoscedasticity/linearity

The model was significant ($p < .001$) (table 9-24) and indicated that parents who identified themselves as being confident in their ability to help their child ($\beta = -.34$, $p < .001$), confident in their parenting skills ($\beta = .21$, $p = .03$) and confident in carrying out the recommendations set by the SLTherapist ($\beta = -.23$, $p < .001$) were more adherent. The overall model fit was $R^2 = .38$ accounting for 38% of the variance in adherence. The difference between R^2 (.38) and the adjusted R^2 (.36) indicated that if this model was obtained from the population rather than a sample it would account for approximately 2% of the variance in any effects (Field 2009).

Therefore, as confidence in helping increases by one standard deviation (4.97), adherence increases by 0.34 SD giving an increase of 4.99 in the degree of adherence (true if confidence in following the recommendations and parenting is held constant). As confidence in following the recommendations increases by 1SD (8.37) adherence increases by 0.23 SD constituting a 3.37 increase in adherence (true if confidence in helping and parenting are held constant). Finally, as confidence in parenting skills increases by 1 SD (22.9), adherence changes by 0.21 SD resulting in a 3.08 increase in the degree of adherence (true if the other two are held constant).

Table 9-24 Summary of hierarchical regression for Parent Beliefs variables predicting Dadh

Variable	Model 1 (N=143)			Model 2 (N=143)		
	B	SEB	β	B	SEB	β
FLQ Parent confidence to help	-1.00	0.23	-0.34**	-0.99	0.25	-.34**
SEPTI-TS Total	0.13	0.05	.21*	0.13	0.06	.21**
SE-SLTR	0.40	0.14	.23**	0.40	0.14	.23**
IPQRSLCN Consequences Child				-0.06	0.37	-0.01
IPQRSLCN self-blame cause				-0.02	0.46	0.00
R ²	0.38			0.38		
F for change in R ²	28.3**			0.01		

*p < .05. **p < .01.

B. Parents personal circumstances: this included demographic, socio-economic and family factors. At baseline the FLQ Family impact subscale was correlated with DAdh ($r_s(147)=.34$ $p<.001$) along with the number of languages spoken in the home ($r_s(147) =.23$ $p=.006$). At follow up the FLQ Family Impact (post) was again associated with DAdh ($r_s(147)=.30$ $p<.001$) as was BTPS Competing Activities/Life Stressors subscale ($r_s(147)=.31$ $p<.0001$). The correlation between Family impact pre and post was high ($r=.70$) and, as the main focus of interest was factors measured at baseline, the follow up factor was not included. Predictors were entered with the number of languages spoken first, given its unchangeable nature, followed by the other baseline measures and then the follow up measure.

This model was checked to ensure that all assumptions were met. The Durbin-Watson statistic confirmed the independence of the observations ($d=2.056$) (an expected value of 2 indicates assumptions met, Field 2009). The scatter plot of standardised predicted value and residuals was indicative of homoscedasticity and of linearity (figure 9-2). There was no evidence of multicollinearity: the predictor variables were not substantially correlated ($r<.9$), the VIF collinearity statistics were well below 10 and the tolerance statistics are greater than 0.2. However, the K-S test was significant $D(145)=0.09$, $p=.003$ indicating that the residuals were not normally distributed. Case wise diagnostics identified three cases with residuals greater than 2 which was within expectations for a sample size of 146. As all had standardised residuals over 2.5 (two over 4), all cases were investigated further. All Cooks distances were

below 1, the centred leverage values were all within twice the size of the average leverage (0.095), and Mahalanobis Distance were acceptable given the sample size; however, the co-variance ratios for all three were outside of the upper limits of acceptable values (range 0.15 to -0.95). These three cases were therefore excluded (cases 45, 104, 197). With their removal the residuals distribution was now considered normal, confirmed by the P-P plot and the non-significant K-S test $D(142)=0.53$, $p=.20$. The final model was therefore improved.

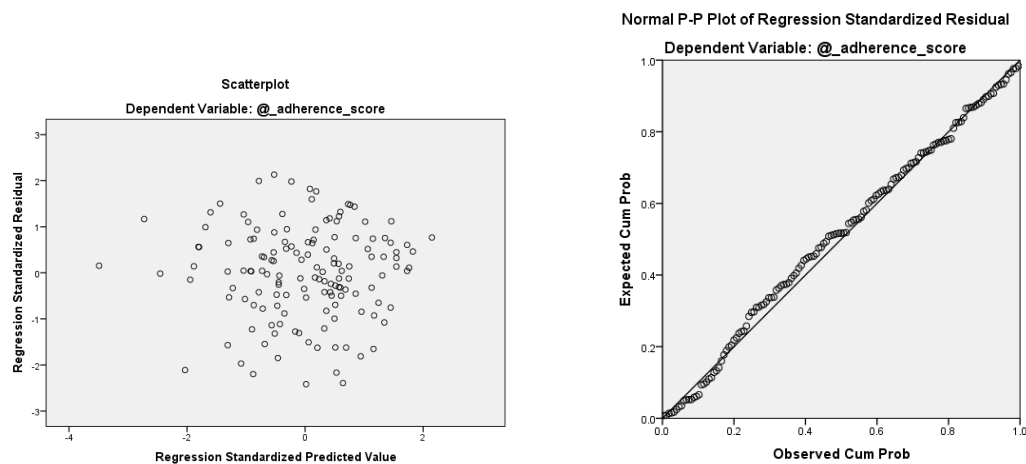


Figure 9-2 Scatterplot & PP plot of standardised residuals: evidence of homoscedasticity/linearity

This model was significant ($p<.001$) and model fit was $R^2=.21$ accounting for 21% of the variance in adherence. The difference between R^2 (.21) and the adjusted R^2 (.19) indicated that if this model was obtained from the population rather than a sample it would account for approximately 2% of the variance in any effects (Field 2009). This model indicates that parents with lower family impact ($\beta = -.39$, $p<.001$) and fewer stressors and competing activities ($SEB=-.24$, $p<.001$) were more adherent (table 9-25).

Therefore, as family impact increases (becomes worse) by one standard deviation (6.12), adherence decreases by 0.39 SD giving a reduction of 6.7 in the degree of adherence (true if no. of language spoken & BTPS variable held constant). As the BTPS competing activities and stressor variable increases (becomes worse) by one standard deviation (5.27), adherence decreases by 0.24 SD constituting a 4.12 increase in adherence (true if no. of language and family impact held constant). The factor 'number of language's' spoken was nonsignificant in the final model.

Table 9-25 Model B: summary of hierarchical regression for Parent Personal Circumstances variables predicting Dadh

N=143	Model 1			Model 2			Model 3		
Variable	B	SEB	β	B	SEB	β	B	SEB	β
Number of languages spoken	5.05	1.92	0.22**	3.42	1.85	0.15	3.36	1.8	0.14
FLQ Family impact				-0.81	0.19	-0.34**	-0.73	0.19	-.39**
BTPS Competing Activities/Life Stressors							-0.66	-0.21	-0.24**
R ²	0.05			0.16			0.21		
F for change in R ²	6.95**			18.1**			9.54**		

*p < .05. **p < .01.

There were no significant relationships with Dadh in any of the measures describing **Child characteristics**. (IPQRSCLN Identity: Total No. Symptoms, Symptoms Related to SLCN, Externalising behaviour symptoms, Language Difficulties, ASD Social Communication symptoms, Other behaviour symptoms. FOCUS baseline. FLQ: Child communication, Child social competence).

C. Parents experience of treatment (baseline): FLQ Treatment Experience was significantly correlated with Dadh ($r_s(147)=.24$ $p=.003$) as was PETS: child improvement ($r_s(147)=.30$ $p<.001$). In the PETS measure both the total expectancies score and the expecting parental involvement domains were also significant. The total score was not used as the credibility domain was not related to Dadh. So, as the largest correlation, only child improvement was used in the model.

Parents experience of treatment (follow up): WAI: Total score was significantly related to Dadh ($r_s(147)=.38$ $p<.001$) as was the BTPS: Treatment issues subscale ($r_s(147)=.25$ $p=.002$), the total numbers of barriers perceived ($r_s(147)=.31$ $p<.001$), the MATIF: importance of recommendation ($r_s(147)=.54$ $p<.001$) and the CSPQ: Total. ($r_s(147)=.34$ $p<.001$). Variables were entered in three blocks with baseline predictors first, followed by the MATIF importance variable and then the remaining follow up predictors. Variables were ordered in relation to the size of the correlation (largest first).

This model was checked to ensure that all assumptions were met. The Durbin-Watson statistic ($d = 2.2$) provided some support that the observations could be considered independent (Field 2009). The scatter plot of standardised predicted value and residuals was indicative of homoscedasticity and of linearity (figure 9-3). There was no evidence of multicollinearity: the predictor variables were not substantially correlated ($r < .9$), the VIF collinearity statistics were well below 10 and the tolerance statistics are greater than 0.2. However, the K-S test was significant $D(147) = 0.09$, $p = .003$, indicating that the residuals were not normally distributed. Case wise diagnostics identified five cases with residuals greater than 2 which was within expectations for a sample size of 148. As all had standardised residuals over 2.5 (two over 3), all cases were investigated further. All Cooks distances were below 1, the centred leverage values were all within twice the size of the average leverage (0.095), and Mahalanobis Distance were acceptable given the sample size; however, the co-variance ratios for all four were outside of the upper limits of acceptable values (range 0.148 to -0.952). These cases were therefore excluded (cases 23, 45, 133, 197) and the residuals distribution was now considered normal, supported by the P-P plot and the non-significant K-S test $D(143) = 0.44$, $p = .20$. The final model was therefore improved.

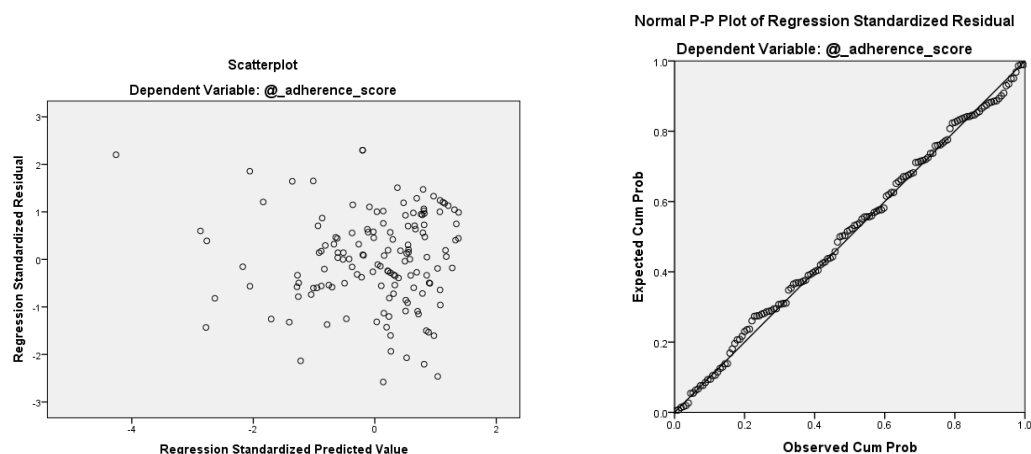


Figure 9-3 Scatterplot & PP plot of standardised residuals: evidence of homoscedasticity/linearity

The model was significant ($p < .001$) (table 9-26) and model fit was $R^2 = .42$ accounting for 42% of the variance in adherence. The difference between $R^2 (.42)$ and the adjusted $R^2 (.39)$ indicated that if this model was obtained from the population rather than a sample it would account for approximately 3% of the variance in any effect (Field 2009). This model indicates that and accounting for all other included variables, as parents rating of the importance of a recommendation increased ($\beta = -.48$, $p < .001$) the degree of adherence also increased. More specifically as importance increased by 1 SD (14.4) adherence increased by 0.48 SD giving an

increase of 6.98 in the degree of adherence (true if all other variables held constant). None of the other included variables reached significance.

Table 9-26 Model C: summary of hierarchical regression for Treatment Experience variables predicting Dadh

Variable	Model 1 (N=144)			Model 2 (N=144)			Model 3 (N=144)		
	B	SEB	β	B	SEB	β	B	SEB	β
FLQ Treatment Experience	-0.59	0.39	-0.12	-0.14	0.34	0.15	-0.06	0.35	-0.01
PETS: child improvement	1.45	0.32	.37**	0.62	0.3	0.16*	0.57	0.3	0.14
MATIF: importance of recommendation				0.54	0.08	.53**	0.48	0.08	.48**
WAI: Total							-0.02	0.1	-0.16
CSPQ: Total							0.1	0.15	0.07
BTPS: total no. barriers							-0.45	0.25	-0.16
BTPS: Treatment issues							0.18	0.46	0.04
R ²	0.18			0.40			0.42		
F for change in R ²	15.4**			50.3**			1.2		

*p < .05. **p < .01.

Combined Model (A-C): All fifteen variables were then entered into the regression, static variables were entered first, followed by each of the previous regressions entered as blocks (N=144). Tests of model assumptions were completed. The Durbin-Watson statistic (d=2.0) provided some support that the observations could be considered independent (Field 2009). The scatter plot of standardised predicted value and residuals was indicative of homoscedasticity and of linearity (figure 9-4). There was no evidence of multicollinearity: the predictor variables were not substantially correlated ($r < .9$), the VIF collinearity statistics were well below 10 and the tolerance statistics are greater than 0.2. Five cases were identified with standardised residuals greater than two and on further examination all five were outside of the upper limits of acceptable values (range 0.148 to -0.952) for covariance ratios and excluded (cases 23, 45, 133,170,197). Following their removal the standardised residuals

distribution was accepted as normal, supported by the P-P plot and the non-significant K-S test $D(138)=0.40$, $p=.20$. This did however, result in a loss of power.

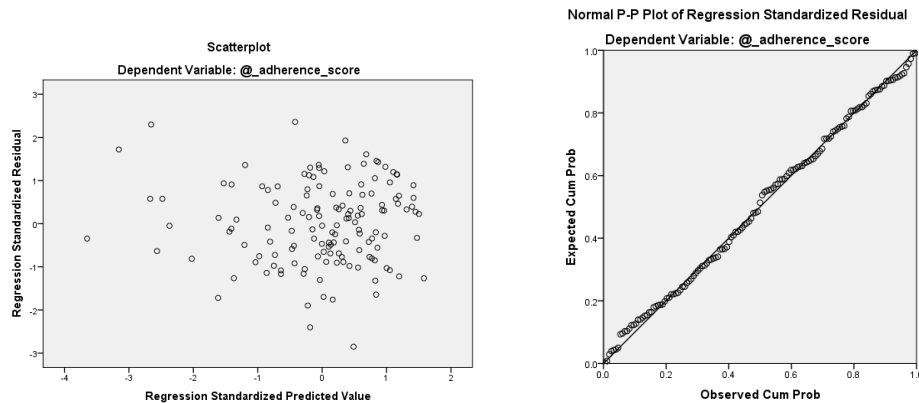


Figure 9-4 scatterplot & PP plot of standardised residuals: evidence of homoscedasticity/linearity

In model 1 (Table 9.27) the co-efficients for number of languages spoken differ slightly between this model and the ‘Parent Personal Circumstances’ model (p. 274, Table 9.25) due to the numbers included. The interpretation of the effect in both models was weak but significant, with no substantive differences.

The final model (4) was significant ($p<.001$) and explained 56% ($R^2=.56$) of the variance in adherence to SLT recommendations at home (table 9-27). The difference between R^2 (.56) and the adjusted R^2 (.51) indicated that if this model was obtained from the population rather than a sample it would account for approximately 5% of the variance in any effect (Field 2009).

Accounting for all other included variables this model indicates that as parents’ ratings of the importance of a recommendation increased ($\beta=-.40$, $p<.001$), the degree of adherence also increased. In addition higher scores of parent confidence to help (i.e. being less confident) ($\beta=-.23$, $p<.001$) resulted in reduced adherence. This can be interpreted as follows: as rated importance of a recommendation increased by 1 SD (14.7) adherence increased by 0.40 SD, giving an increase of 5.88 in the degree of adherence (true if all other variables held constant). And, as parents ratings of confidence in being able to help their child increased by 1SD (4.94) adherence decreased by 1 SD (14.7) (i.e. a 3.38 decrease in the degree of adherence). Parents confidence in following the recommendations also predicted adherence ($\beta=.16$, $p=.04$) interpreted as a 1SD increase (8.13) in this confidence resulting in a 1SD (14.7) i.e. a 2.5 increase in the degree of adherence. However, the effect size is less than .20 so conclusions are limited. None of the other included variables reached significance.

In summary, better adherence was observed in parents who assigned greater importance to the recommendations; who were confident in helping their child with SLCN and, were confident in following the recommendations provided by a SLTherapist.

Table 9-27 Full model: summary of hierarchical regression for all variables predicting Degree of Adherence (Dadh)

N=139	Model 1			Model 2			Model 3			Model 4		
Variable	B	SEB	β	B	SEB	β	B	SEB	β	B	SEB	β
No. languages spoken	5.98	1.9	.26**	4.03	1.78	.18*	2.19	1.63	0.1	0.59	1.54	0.03
FLQ Family impact				-0.74	0.18	-.32**	-0.21	0.2	-0.09	-0.22	0.18	-0.09
BTPS Competing Activities/Life				-0.67	0.22	-.24**	-0.28	0.2	-0.1	-0.13	0.31	-0.04
FLQ Parent confidence to help							-0.86	0.25	-.29**	-0.68	0.24	-.23**
SEPTI-TS Total							0.1	0.06	0.16	0.08	0.06	0.13
SE-SLTR							0.39	0.14	.22**	0.28	0.13	.16*
IPQRSLCN Consequences Child							0.18	0.38	0.04	0.34	0.36	0.08
IPQRSLCN self-blame cause							-0.13	0.45	-0.02	0.01	0.41	0.002
FLQ Treatment Experience										0.26	0.36	0.06
PETS: child improvement										0.27	0.28	0.07
MATIF: importance recommendation										0.39	0.08	.40**
WAI: Total										0.003	0.09	0.003
CSPQ: Total										0.01	0.14	0.01
BTPS: total no. barriers										-0.04	0.39	-0.02
BTPS: Treatment issues										0.2	0.46	0.04
R ²	0.07			0.24			0.43			0.56		
F for change in R ²	9.86**			15.2**			8.68**			5.18**		

*p < .05. **p < .01.

NB: The β at entry for No. language spoken differs from that shown in Table 9.25 due to the difference in sample sizes between analyses.

9.4.3 Predicting child outcome

AIMS:

1. To identify whether attendance and adherence are related to child outcome.
2. To determine the extent to which parental factors (beliefs, experience of treatment, personal circumstances), child characteristics and actual treatment, relate to child outcome.

Hypotheses:

1. Child outcome will be related to non-attendance and adherence.
2. Predictors of child outcome will include parental factors (personal circumstances, beliefs: child problem, self-efficacy; experience of treatment), child characteristics and treatment variables.

In order to test **hypothesis 1**, correlations were examined between non-attendance, adherence and child outcome (table 9-28) as well as assessing overall contributions within regression models.

Missed appointments (DNA) was significantly correlated with FOCUS follow up ($r(147)=-.17$ $p=.05$); however, as the effect size is less than .20 it was not included as a variable in predicting child outcome. Adherence (Dadh) was also significantly correlated with FOCUS follow up ($r(147) = .21$ $p = .01$) and was included in the predicting child outcome analyses. Attendance and adherence were unrelated.

Table 9-28 Correlations between main Outcome variables: Non-attendance (DNA), Adherence (Dadh), Child Outcome (FOCUS follow up).

		DNA	Dadh	FOCUS follow up
DNA	Correlation Coefficient	1.00	-0.07	-.168*
	Sig. (2-tailed)		0.37	0.04
	N	199.0	148.0	147.0
Dadh	Correlation Coefficient	-0.07	1.00	.214**
	Sig. (2-tailed)	0.37		0.01
	N	148.0	148.0	147.0
FOCUS Follow up	Correlation Coefficient	-.168*	.214**	1.00
	Sig. (2-tailed)	0.04	0.01	
	N	147.00	147.00	147.00

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

In order to test **hypothesis 2**, correlations between factors within the four domains and child outcome were examined. Those with effect sizes greater than .20 (table 9-29) were subsequently included in regression analyses with each domain treated separately before being considered as a single model predicting child outcome.

Child Outcome was measured using the parent-rated FOCUS follow-up score whilst accounting for the baseline score (by entering it as a predictor in the model). Correlations between all study factors were examined to identify relevant factors for inclusion in a regression model. Total scores were used when all subdomains of a scale demonstrated significant correlations to minimise risk of multicollinearity and to enhance power. Factors were separated into baseline and follow-up. Table 9-29 reports all significant correlations and, in keeping with the requirement of only including effect sizes greater than .2; this resulted in fifteen potential factors at baseline and four at follow up. The MCID was a 16 point change in FOCUS scores (Thomas-Stonell et al., 2013).

At baseline five factors were located in the child features domain: the age of the child ($r(147)=.43$ $p=.001$), the number of SLCN descriptors used by a SLTherapist ($r(147)=-.29$ $p=.01$), the communication subscale of the FLQ ($r(147)=-.58$ $p=.001$), the social competence subscale of the FLQ ($r(147)=-.68$ $p=.001$) and the total number of symptoms reported in the IPQR ($r(147)=.50$ $p=.001$). One was treatment related: the number of different types of intervention provided by SLT ($r(147)=.21$ $p=.01$). Seven factors were from the parent beliefs domain, five referred to beliefs about their child's problem and two were self-efficacy beliefs. Child problem beliefs included timeline beliefs ($r(147)=-.34$ $p=.001$), overall consequences for the parent and child ($r(147)=-.39$ $p=.001$) beliefs in the Cyclical nature of SLCN ($r(147)=-.26$ $p=.002$) and parents emotional representations ($r(147)=-.34$ $p=.001$). Self-efficacy beliefs relating to parents overall confidence in parenting ($r(147)=.32$ $p=.001$) and in helping their child ($r(147)=-.28$ $p=.001$). The remaining factor was from the parent personal circumstance domain: family impact ($r(147)=-.32$ $p=.001$).

At follow up all factors pertained to the 'Parent Experience of Treatment' domain: degree of adherence ($r(147)=.21$ $p=.01$), WAI total ($r_s(147)=.34$ $p=.001$), the total number of barriers (BTPS total) ($r(147)=-.26$ $p=.01$) and total satisfaction (CSPQ) ($r_s(147)=.34$ $p=.001$).

Table 9-29 Correlations with FOCUS follow-up score

	N	Correlation	Sig. (2-tailed)
Baseline			
FOCUS baseline	147	.81	.001
Child Characteristics			
Child age	147	.43	.001
No. of SLCN descriptors	147	-.29	.001
FLQ communication	147	-.58	.001
FLQ social	147	-.68	.001
IPQRId Sum	147	.50	.001
Treatment data			
No. different types of intervention	147	.21	.01
Sessions offered intervention	147	-.17	.04
Parent Beliefs (child problem)			
IPQRViews Timeline	147	-.34	.001
IPQRViews Consequences (total)	147	-.39	.001
IPQRViews Treatment Control	147	.18	.03
IPQRViews Timeline Cyclical	147	-.26	.002
IPQRViews Emotional representations	147	-.34	.001
Parent beliefs (self-efficacy)			
FLQ Confidence to help	147	-.28	.001
SEPTI total	147	.32	.001
Personal circumstances			
FLQ family impact	147	-.32	.001
Follow up			
Treatment Experience			
Missed appointments	147	-.17	.04
Degree of adherence	147	.21	.01
WAI Total	147	.34	.001
BTPS Total no. barriers	147	-.26	.001
Total CSPQ (18)	147	.34	.001

Three separate regressions were conducted to represent baseline, follow up and combined models. Each model was checked to ensure that all assumptions were met.

The Durbin-Watson statistic confirmed the independence of the observations for each model ($d=1.91-2.06$) (expected value of 2 indicates assumptions met, Field 2009). Case wise diagnostics identified four cases with residuals greater than 2, which was within expectations for a sample size of 147 (where 8 cases (5%) would have been expected to have values over 2) (Field 2009). Two cases had standardised residuals over 2.5 which was within the expected 1%; however, with their removal the Durbin Watson statistic improved in each regression. No further case analysis was considered necessary. The scatter plot of standardised predicted value and residuals was also improved with the removal of these two cases and indicative of homoscedasticity and of linearity (figures 9-5 to 9-7). There was no evidence of multicollinearity: the predictor variables were not substantially correlated ($r < .9$), the VIF collinearity statistics were well below 10 and the tolerance statistics were greater than 0.2. A K-S test was non-significant $D(145) = 0.74$, $p=.74$ indicating that the residuals were normally distributed.

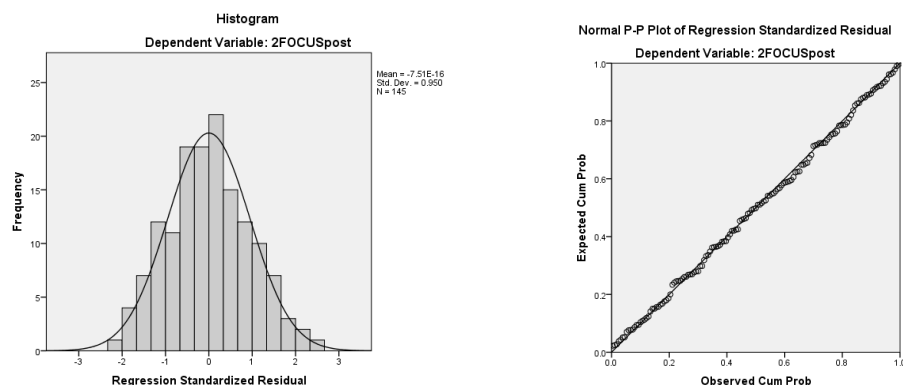


Figure 9-5 Baseline Model: scatterplot & PP plot of standardised residuals: evidence of homoscedasticity/linearity

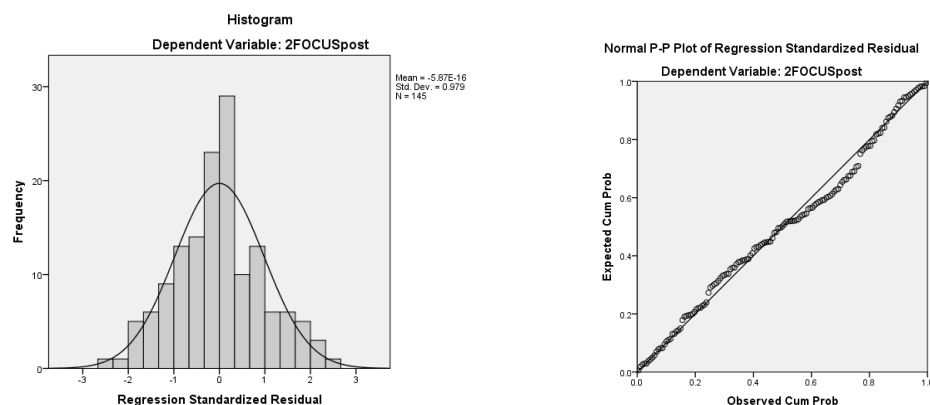


Figure 9-6 Follow-up Model: scatterplot & PP plot of standardised residual: evidence of homoscedasticity/linearity

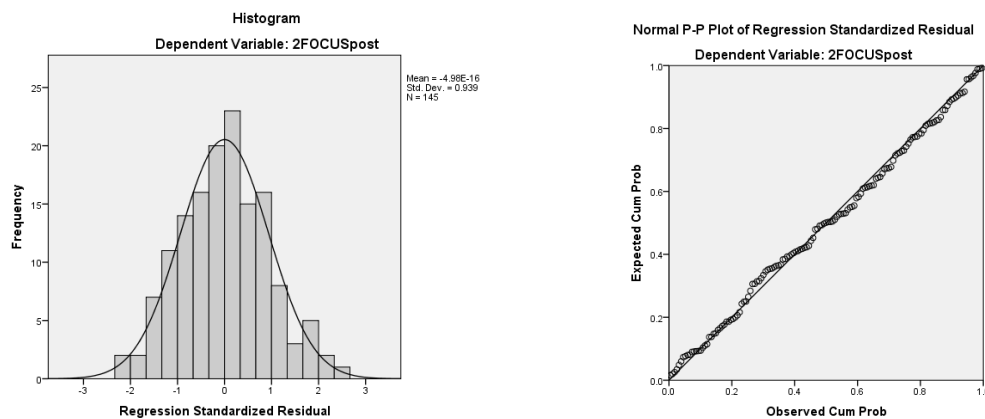


Figure 9-7 Combined Model: scatterplot & PP plot of standardised residuals: evidence of homoscedasticity/linearity

Baseline model

Dependant variables were entered in blocks; block one included FOCUS baseline score, block two included child variables, treatment data were added in block three, parent beliefs (child problem and self-efficacy) were added to block five, and finally the factor related to parent personal circumstances was added to block six. Changes in R^2 were significant up to and including block two. The addition of treatment variables in block three did not result in an improved model, but the addition of parent beliefs in block four did. Although the SEPTI total variable (parenting self-efficacy) was significant in model five, the addition of this and the two other variables in this model, together only explained an additional 1% of the variance. Model four was therefore assessed as the best fitting model (table 9-30). Power was reduced as the sample size was less than expected ($N=145$).

Model four was significant ($p=.001$) and explained 73% ($R^2=.73$) of the variance in child outcome as measured by FOCUS scores at follow up. The difference between R^2 ($=.73$) and the adjusted R^2 ($=.71$) indicated that if this model was obtained from the population rather than a sample, there would be a 2% variance in effects (Field 2009). This model indicates that baseline scores on the FOCUS ($\beta=.68$, $p<.01$), parent ratings of child social competence (i.e. a child has better skills) ($\beta=-.26$, $p<.01$), total number of symptoms ($\beta=.18$, $p<.01$), and beliefs about timeline of SLCN ($\beta= -.14$, $p<.01$) predicted child outcome, as measured using FOCUS follow up scores. None of the other included variables reached significance.

This can be interpreted as follows: as the baseline rating of the FOCUS increased by 1 SD (57.6) FOCUS follow up scores increased by 0.68 SD (62.9), giving an increase of 42.8 (true if all other variables held constant), a MCID. And, the endorsement of child social competence decreased by 1SD (4.47) FOCUS follow up scores increased by 0.26 SD (62.9) i.e. a 16.4 point increase in child outcome (true if all other variables held constant), a MCID. As the total number of symptoms increased by 1SD (4.87) FOCUS follow up scores increased by 0.18 SD (62.9) i.e. an 11.3 point increase in FOCUS follow up. Finally as the timeline score decreased by 1SD (3.18) FOCUS follow ups cores increased by 0.14 SD (62.9) i.e. an 8.0 point increase in child outcome (true if all other variables held constant).

Children whose communication abilities were rated higher on the FOCUS by their parents at the beginning of the study, whose parents rated them as being more socially competent, resulted in better child outcome as rated by parents, with a MCID. These children also had a greater number of parent-reported symptoms in total, and their parents believed their child's SLCN was short in duration, although a MCID was not observed.

Table 9-30 Summary of hierarchical regression analysis for all Baseline variables predicting child outcome

N=145	Model 1			Model 2			Model 3			Model 4-Preferred			Model 5			Model 6		
Variable	B	SEB	β	B	SEB	β	B	SEB	β	B	SEB	β	B	SEB	β	B	SEB	β
FOCUS Baseline	0.90	0.05	0.82**	0.72	0.09	0.65**	0.71	0.09	0.65**	0.75	0.09	0.68**	0.73	0.09	0.67**	0.72	0.09	0.66**
Child age				0.19	0.38	0.03	0.19	0.38	0.03	0.28	0.39	0.04	0.42	0.39	0.06	0.43	0.39	0.06
FLQ: social competence				-3.99	1.10	-	-	1.10	-	-3.69	1.09	-0.26**	-3.50	1.08	-0.25**	-3.53	1.08	-0.25**
IPQRId sum				1.40	0.81	0.11	1.42	0.81	0.11	2.32	0.91	0.18**	2.48	0.91	0.19**	2.27	0.99	0.18*
FLQ: communication				-0.42	1.53	-0.02	-	1.53	-0.02	-0.15	1.52	-0.01	-0.08	1.49	0.00	-0.07	1.50	0.00
No. intervention types							-	3.99	-0.05	-1.71	4.01	-0.02	-2.08	3.98	-0.02	-2.13	3.99	-0.03
IPQRViews Timeline										-2.07	0.82	-0.14**	-2.28	0.81	-0.15**	-2.37	0.83	-0.16**
IPQRViews Consequences										-0.34	0.67	-0.04	-0.27	0.66	-0.03	-0.29	0.66	-0.03
IPQRViews Illness coherence										-0.61	0.90	-0.04	-1.11	0.91	-0.06	-1.16	0.92	-0.07
IPQRViews timeline cyclical										-1.91	1.18	-0.10	-1.84	1.18	-0.09	-1.81	1.19	-0.09
IPQRViews Emotional Reps.										1.10	0.82	0.09	1.21	0.82	0.10	1.20	0.83	0.10
FLQ Confidence to help													-0.01	0.71	0.00	-0.10	0.73	-0.01
SEPTI total													0.33	0.15	0.12*	0.35	0.16	0.13*
FLQ Family impact																0.36	0.67	0.04
R ²	0.67			0.71			0.71			0.73			0.74			0.74		
adj R ²	0.67			0.70			0.70			0.71			0.72			0.72		
F change in R ²	291.5*			4.12**			0.98			2.26*			2.84			0.3		

*p < .05. **p < .01.

Follow up model

All dependant variables correlated with FOCUS follow up score were from the Treatment experience domain and were entered in blocks. Block one included FOCUS baseline score, block two included degree of adherence, the therapeutic alliance total score was added in block three, overall satisfaction with SLT was added to block five, and finally the total number of barriers to treatment was added to block six. Changes in R^2 were significant up to and including block two. The addition of variables in block three did not result in an improved model, but the addition of parental satisfaction beliefs in block four did. The addition of total number of barriers did not improve the model significantly; therefore model four was the best fitting model (table 9-31). Power was reduced as a result of a sample size that was less than expected ($N=145$).

Model four was significant ($p<.01$) and explained 70% ($R^2=.70$) of the variance in child outcome as measured by FOCUS scores at follow up. There was no difference between R^2 ($=.70$) and the adjusted R^2 ($=.70$) indicating that this model was representative of the population (Field 2009). This model indicates that baseline scores on the FOCUS ($\beta= .68$, $p<.01$), and parents satisfaction with SLT ($\beta = .17$, $p=.02$) predicted child outcome, as measured FOCUS follow up scores. None of the other included variables reached significance. This can be interpreted as follows: as the baseline rating of the FOCUS increased by 1 SD (57.6) FOCUS follow up scores increased by 0.70 SD (62.9), giving an increase of 44 points (true if all other variables held constant). And, as parent satisfaction with SLT increased by 1SD (10.1) FOCUS follow up scores increased by 0.17 SD (62.9) i.e. a 10.7 point increase in child outcome (true if all other variables held constant).

Children whose communication abilities were rated higher on the FOCUS by their parents at the beginning of the study, resulted in improved child outcome as rated by parents, with a MCID. These parents reported greater satisfaction with SLT services, but this did not reflect a MCID.

Table 9-31 Summary of hierarchical regression for all follow-up variables predicting child outcome

N=145	Model 1			Model 2			Model 3			Model 4			Model 5		
Variable	B	SEB	β	B	SEB	β	B	SEB	β	B	SEB	β	B	SEB	β
FOCUS Baseline	0.90	0.05	0.82**	0.89	0.05	0.81**	0.87	0.05	0.79**	0.86	0.05**	0.78	0.86	0.05	0.78**
Degree of Adherence				0.49	0.17	0.13**	0.41	0.18	0.11*	0.31	0.18	0.09	0.31	0.19	0.09
WAI total							0.26	0.22	0.06	-0.21	0.29	-0.05	-0.24	0.30	-0.06
CSPQ total										1.06	0.44*	0.17	1.05	0.44	0.17*
Total no. barriers													-0.23	0.63	-0.02
R ²	0.67			0.69			0.69			0.70			0.70		
adj R ²	0.67			0.68			0.69			0.70			0.69		
F change in R ²	291.5**			8.22**			1.41			5.78*			0.13		

*p < .05. **p < .01.

Full model (baseline and follow up predictors)

Dependant variables were added in blocks as previously described in the baseline and follow up regression analyses. The only exception was that variables which were in non-preferred models for baseline and follow up predictors were added as the final block. With the exception of model 3 and model 7, the addition of blocks significantly improved model fit. The best fitting model was model six (table 9-32). Power was reduced as a result of a sample size that was less than expected (N=145).

Model six was significant ($p < .001$) and explained 76% ($R^2 = .76$) of the variance in child outcome as measured by FOCUS scores at follow up (table 9-32). The difference between R^2 ($= .76$) and the adjusted R^2 ($= .74$) indicated that if this model was obtained from the population rather than a sample there would be a 2% variance in effects (Field 2009). This model indicates that baseline scores on the FOCUS ($\beta = .65$, $p < .01$), parent ratings of child social competence (i.e. a child has better skills) ($\beta = -.24$, $p < .01$), total number of symptoms ($\beta = .15$, $p < .01$), beliefs about timeline of SLCN ($\beta = -.13$, $p < .05$), and in a cyclical timeline ($\beta = -.12$, $p < .05$), and parents satisfaction with SLT ($\beta = .20$, $p = .02$) predicted child outcome, as measured FOCUS follow up scores. None of the other included variables reached significance.

This can be interpreted as follows: as the baseline rating of the FOCUS increased by 1 SD (57.6) FOCUS follow up scores increased by 0.65 SD (62.9), giving an increase of 40.9 points (true if all other variables held constant). And, as the endorsement of child social competence decreased (skills improving) by 1SD (4.47) FOCUS follow up scores increased by 0.24 SD (62.9) i.e. a 15.1 point increase in child outcome (true if all other variables held constant). As the total number of symptoms increased by 1SD (4.87) FOCUS follow up scores increased by 0.15 SD (62.9) i.e. an 9.44 point increase in FOCUS follow up. As the timeline score decreased by 1SD (3.18) FOCUS follow up scores increased by 0.13 SD (62.9) i.e. a 8.18 point increase in child outcome (true if all other variables held constant). As the timeline cyclical score decreased by 1SD (3.18) follow up scores increased by 0.12 SD (62.9) i.e. a 7.55 point increase in child outcome. Finally as parent satisfaction with SLT increased by 1SD (10.1) FOCUS follow up scores increased by 0.20 SD (62.9) i.e. a 12.6 point increase in child outcome (true if all other variables held constant).

Children, whose communication abilities were rated higher on the FOCUS by their parents at the beginning of the study, achieved a better outcome as rated by parents and with a MCID. These parents rated them as being more socially competent at this time with the change almost reaching MCID (15.1 versus 16 point increase). These children presented with a greater number of parent-reported symptoms in total; their parents believed their SLCN was short in duration, constant rather than cyclical, and reported greater satisfaction with SLT services. However, none of these factors resulted in a MCID.

Adherence (Dadh) was a significant predictor in model 5, but the addition of satisfaction in model 6 reduced the effects. Of the predictors in model 6, adherence was significantly related to WAI total ($r_s(148)=.38$ $p=.001$), and CSPQ total ($r_s(148)=.34$ $p=.001$). IPQR-SLCN consequences and emotional representations were also significantly correlated with Dadh, but all effect sizes were less than .20.

Table 9-32 Summary of hierarchical regression for all variables predicting child outcome

N=145	Model 1			Model 2			Model 3			Model 4			Model 5			Model 6-Best fitting			Model 7		
Variable	B	SEB	β	B	SEB	β	B	SEB	β	B	SEB	β	B	SEB	β	B	SEB	β	B	SEB	β
FOCUS Baseline	0.90	0.05	.82**	0.72	0.09	.65**	0.71	0.09	.65**	0.75	0.09	.68**	0.73	0.09	.67**	0.71	0.09	.65**	0.70	0.09	.63**
Child age				0.19	0.38	.03	0.19	0.38	.03	0.28	0.39	.04	0.27	0.38	.04	0.23	0.37	.03	0.29	0.38	.04
FLQ: social compet.				-	1.10	-.28**	-3.94	1.10	-.28**	-3.69	1.09	-.26**	-3.53	1.06	-.25**	-3.42	1.03	-.24**	-3.35	1.04	-.24**
FLQ: commun.				-	1.53	-.02	-0.39	1.53	-.02	-0.15	1.52	-.01	-0.27	1.48	-.01	-0.68	1.45	-.03	-0.80	1.46	-.04
IPQRid sum				1.40	0.81	.11	1.42	0.81	.11	2.32	0.91	.18**	2.21	0.89	.17**	1.99	0.87	.15*	1.87	0.96	.14*
No. interv. types							-3.94	3.99	-.05	-1.71	4.01	-.02	-2.44	3.96	-.03	-3.10	3.86	-.04	-3.05	3.95	-.04
IPQVR Timeline										-2.07	0.82	-.14**	-1.90	0.80	-.13*	-1.94	0.78	-.13*	-2.19	0.80	-.15**
IPQRV Conseq.										-0.34	0.67	-.04	-0.17	0.66	-.02	-0.12	0.64	-.01	-0.16	0.64	-.02
IPQRV coherence										-0.61	0.90	-.04	-0.70	0.88	-.04	-1.02	0.86	-.06	-1.32	0.91	-.08
IPQRV time-cyclical										-1.91	1.18	-.10	-2.30	1.18	-.12*	-2.30	1.15	-.12*	-2.01	1.17	-.10
IPQRV Emot. Reps.										1.10	0.82	.09	1.25	0.80	.10	1.43	0.78	.11	1.39	0.80	.11
Degree Adherence													0.38	0.17	.10*	0.27	0.17	.07	0.25	0.19	.07
WAI total													0.25	0.22	.06	-0.27	0.28	-.07	-0.38	0.29	-.09
CSPQ total																1.22	0.42	.20**	1.21	0.42	.19**
FLQ Confid to help																			0.57	0.75	.04
SEPTI total																			0.24	0.16	.09
FLQ Family impact																			0.28	0.65	.03
Total no. barriers																			-0.54	0.63	-.04
R ²	.67			.71			.71			.73			.75			.76			.77		
adj R ²	.67			.70			.70			.71			.72			.74			.74		
F change in R ²	291.5**			4.12**			0.99			2.26*			4.65**			8.39**			0.83		

*p < .05. **p < .01.

9.5 Post Hoc Analyses

Post hoc analyses were undertaken as an attempt to characterise participants further. Participants were divided into two groups based on the median score (a 'median split') for the predictor variable and the pattern of means for 'other' variables examined across each group. While this approach has various limitations, such as reduced power (Rucker et al., 2105) and an assumption of linearity (Gelman & Park, 2008), it can be useful in post-hoc exploratory analyses where the aim is for additional interpretation of findings rather than inference (Iacobucci et al., 2015). In this instance, the 'median split' provides a simple means for describing the differences in the beliefs and experiences of participants according to each predictor variable.

9.5.1 Exploring Participant Characteristics: predictors of attendance

The predictors of attendance were maternal final education level, maternal age, parents' belief in an early medical cause and parents' confidence in being able to provide instrumental care. Each predictor was treated separately. Non-parametric tests were used for data with non-normal distributions.

Group differences: Maternal Education Level

The sample (baseline N=199, follow-up=147) was split into two groups based on the median rating of 3, representing an achievement of achieving GCSE's or equivalent. Group one included participants educated to GCSE level or less (n=73), and group two, A level or equivalent (rating of 4) and above (n=125). Significant differences were observed in the following domains:

Parent beliefs: child problem: On average parents in group 1 (lower level of education) (\bar{X} =11.2) gave a greater endorsement to the belief that their child's SLCN was cyclical in nature (IPQR timeline cyclical) than group 2 (\bar{X} =9.36), $t(196)=3.90$, $p=.001$ with a small to medium effect size ($r=.28$).

Treatment experiences: Parents in group 1 (Mdn=22) reported experiencing fewer competing activities/stressors (BTPS) than those in group 2 (Mdn=24) $U=1793.5$, $Z=-2.42$, $p=.001$ with a small effect size ($r=-.20$).

These results indicate that less educated mothers, who miss more SLT appointments, are more likely to think their child's problem is fluctuating, and experience fewer competing activities or stressors.

Group differences: Maternal Age

The sample (baseline N=199, follow up=147) was split into two groups based on the median age of 35. Group 1 included mothers who were younger than 35 years (n=91) and group 2 those who were 35 and older (n=102). Significant differences were observed between the two groups across a number of baseline variables and are reported below; only those with effect sizes greater than .2 are included.

Parent beliefs: child problem: On average parents in group 1 (younger mothers) gave a higher endorsement of a child related cause (IPQR) (\bar{X} =7.59) than those in group 2 (\bar{X} =6.66), $t(190) = 2.89$, $p = .004$, with a small to medium effect size ($r=.21$). Parents in group 1, on average, reported fewer consequences of their child's SLCN (IPQR) (\bar{X} =6.17) than group 2 (\bar{X} =7.62), $t(191) = 2.99$, $p = .003$ with a small to medium effect size ($r=.21$). Parents in group 1 held a greater belief that their child's SLCN was cyclical in nature (\bar{X} =10.9) (IPQR timeline cyclical) than parents in group 2 (\bar{X} =9.16), $t(191)=3.61$, $p=.001$, with a small to medium effect size ($r=.26$).

Child characteristics: Parents in group 1 reported a greater number of symptoms in their child overall (Mdn=13) than parents in group 2 (Mdn=10.5), $U=3175.5$, $Z=-3.79$, $p=.001$, with a small to medium effect size ($r=-.31$).

These findings would suggest that younger mothers, who are more likely to miss SLT appointments, report that their children with SLCN have more symptoms. These parents also held greater beliefs in child-related causes and thought their child's problem was cyclical. They also believed that their child's SLCN had fewer consequences for their child and themselves.

Group differences: Causal beliefs resulting from an early medical experience

The sample (baseline N=199, follow up =147) was split into two groups based on the median rating of 10 of an early medical cause. Group one included participants with scores less than ten (n=86) and group two included those with scores greater than or equal to 10 (n=112).

Parent beliefs: child problem: Significant differences were observed between the group means in all other domains of causal beliefs. Parents in group 1 endorsed fewer external causes (IPQR) ($\bar{X}=8.92$) than those in group 2 ($\bar{X}=12.1$), $t(196)=-8.01$, $p=.001$, with a medium effect size ($r=.58$). The causal attribution of self-blame was also endorsed less in group 1 ($\bar{X}=5.77$) than group 2 ($M=7.09$), $t(196)=-3.89$, $p=.001$ with a small to medium effect size ($r=.28$). Parents in group 1 ($Mdn=43$) believed they had greater control over their child's SLCN (IPQR Control parent) than parents in group 2 ($Mdn=40$) $U= 4176.5$, $Z=-1.61$, $p=.001$, with a small to medium effect size ($r=.34$).

Child characteristics: Parents in group 1 reported fewer child symptoms overall (IPQRId Total) ($Mdn=10.5$) than those in group 2 ($Mdn=13$), $U= 3715.5$, $Z=-2.76$, $p=.001$ with a medium effect size ($r=.54$).

Parents who gave a lower endorsement of the causal belief of an early medical experience and who are less likely to miss appointments, gave lower endorsements of the causal beliefs of an external cause, and self-blame. These parents also reported fewer symptoms overall in their child and believed they were in control of their child's SLCN.

Group differences: Parenting self-efficacy-instrumental care

The sample (baseline $N=199$, follow up $=147$) was split into two groups based on the median score of 38 for the instrumental care domain of the SEPTI-TS. Group one included participants with scores less than 38 ($n=98$), group two included those with scores equal to or more than 38 ($n= 100$). Significant differences between the group means were observed in the following areas

Parent personal circumstances: Parents in group 1 reported higher scores on FLQ family impact ($Mdn=18.5$) than those in group 2 ($Mdn=14$), $U=3194.5$, $Z=-4.33$, $p=.001$, with a small to medium effect size ($r=-.30$).

Parent beliefs: child problem: Participants in group 1 gave a higher endorsement of the causal attribution of self-blame ($Mdn=6$) than those in group 2 ($Mdn=6$), $U=3357.5$, $Z=-3.92$, $p=.001$, with a small to medium effect size ($r=-.28$). (Note: although the median scores were equal in both groups, the means did differ: 1 $\bar{X}=5.94$, group 2 $\bar{X}=7.10$). Beliefs in an external cause was

also higher in group 1 (\bar{X} =11.6) than group 2 (\bar{X} =9.86), $t(196) = 4.03$, $p = .001$ (small-medium effect size $r=.29$). They also endorsed early medical experiences as cause to a greater degree (Mdn=10) than parents in group 2 (Mdn=8), $U=3497$, $Z=-3.61$, $p= .001$, with a small to medium effect size ($r=-.26$). Participants in group 1, on average, also reported more consequences for both them and their child (\bar{X} =26.0) than those in group 2 (\bar{X} =22.3), $t(197)=3.81$, $p=.001$, with small to medium effect sizes ($r=.27$). Group 1 indicated that their view of their child's SLCN was less coherent (IPQR illness coherence) (\bar{X} =17.4) than those in group 2 (\bar{X} =19.0), $t(197)=-3.13$, $p=.002$, with a small to medium effect size ($r=.22$).

Parent beliefs: self-efficacy: On average participants in group 1 reported lower levels of self-efficacy to teach their child (SEPTI teach) (Mdn=41) than those in group 2 (Mdn=44) $U=2975$, $Z=-4.87$, $p=.001$ with a small to medium effect size ($r=-.35$). Participants in group 1 were less confident in disciplining their child (SEPTI discipline) (\bar{X} =24.3) than those in group 2 (\bar{X} =27.8), $t(197)=-6.04$, $p=.001$, with a small to medium effect size ($r=.44$).

Child characteristics: On average participants in group 1 reported a greater number of total child symptoms (IPQRId Total) (\bar{X} =13.8) than those in group 2 (\bar{X} =10.7), $t(197)=4.67$, $p=.001$ with a small to medium effect size ($r=.33$). Group 1 participants also identified more symptoms that were related to their child's SLCN (Mdn=8) than group 2 (Mdn=6), $U=3821$, $Z=-2.79$, $p=.001$, with a small to medium effect size ($r=-.20$). Group 1 participants believed their child had more externalising behaviour symptoms (\bar{X} =2.04) than group 2 (\bar{X} =1.43), $t(197)=3.16$, $p=.002$, with a small to medium effect size ($r=.22$).

Parents who report less confidence in providing instrumental care for their child and who are more likely to miss SLT appointments also have less confidence in teaching and disciplining their child. They perceive that their child's SLCN has a greater impact on the family and endorse greater consequences. These parents also reported a greater number of causes in a number of domains, and understood their child's difficulties less. They describe their children with SLCN as displaying more externalising behaviours and a greater number of symptoms including those related to SLCN.

9.52 Exploring Participant Characteristics: predictors of adherence

The same approach was employed for the main predictors of adherence. Non-parametric tests were used for data with non- normal distributions.

Group differences: importance of a recommendation

The sample (N=147) was split into two groups based on the median score of 92 of the degree of importance assigned to a recommendation. Group one included participants with scores less than 92 (n=69) and group two those with 92 or more (n= 78). Significant differences between the means of the groups were observed in all four domains under study:

Parent personal circumstances: Parents in group 1 (lower importance ratings) rated FLQ family impact higher (indicating an increased impact) (Mdn = 19) than group 2 (Mdn = 15), $U=1943.5$, $Z=-2.91$, $p=.004$ with a small to medium effect size ($r=-.24$).

Parent beliefs (child problem): On average parents in group 1 ($\bar{X}=26.5$) reported more consequences (IPQR) in total than those in group 2 ($\bar{X}=22.7$), $t(145)=3.52$, $p=.001$ with a small to medium effect size ($r=.29$)

Parent beliefs (self-efficacy): On average parents in group 1 ($\bar{X}=17.5$) gave higher scores on the FLQ Confidence to help factor (indicating reduced confidence) than those in group 2 ($\bar{X}=14.4$) $t(145)=3.97$, $p=.001$ with a medium effect size ($r=.33$). Parents in group 1 (Mdn=208) also reported a lower level of overall confidence in their parenting (SEPTI total) than those in group 2 (Mdn=222) $U=1718$, $Z=-3.78$, $p=.001$ with a medium effect size ($r=-.31$). Group 1 (Mdn=45) parents also had lower confidence in following the SLT recommendations (SE total) than group 2 (Mdn=48), $U=2061$, $Z=-2.45$, $p=.01$ with a small to medium effect size ($r=-.20$).

Child characteristics: On average parents in group 1 reported a higher total number of symptoms in their child ($\bar{X}=13.4$) (IPQR Id Related to) than those in group 2 ($\bar{X}=11.4$), $t(145)=2.54$, $p=.01$ small to medium effect size ($r=.21$).

Treatment experiences: On average parents in group 1 ($\bar{X}=72.7$) had lower expectations of treatment at baseline (PETS total) than group 2 ($\bar{X}=78.5$), $t(147)=-4.93$, $p=.001$ with a medium effect size ($r=-.42$). Parents in group 1 (Mdn=24) also reported more competing

activities/stressors (BTPS) than group 2 (Mdn=21), $U=1860.5$, $Z=-3.24$, $p=.001$ with small to medium effect size ($r=-.27$), more Treatment Issues (BTPS) (group 1 Mdn=10, group 2 Mdn=8), $U=1935.5$, $Z=-3.10$, $p=.002$ with a small to medium effect size ($r=-.26$). Group 1 (Mdn=9). Parents rated the relevance of treatment (BTPS) lower than group 2 (Mdn=8), $U=1809$, $Z=-3.74$, $p=.001$ with medium effect size ($r=-.31$) and also reported a greater number of barriers overall (BTPS Total Barriers) (group 1 Mdn=6, group 2 Mdn=3), $U=1810.5$, $Z=-3.43$, $p=.001$ with a small to medium effect size ($r=-.28$). Finally parents in group 1 (Mdn=71) were overall less satisfied than those in group 2 (Mdn=77), $U=1606.5$, $Z=-4.21$, $p=.001$ with a medium effect size ($r=-.35$).

This means that parents in the group with lower importance ratings and who were likely to have a lower degree of adherence, reported more symptoms, had lower parenting self-efficacy in general, lower ratings of confidence in following the recommendations and reduced confidence in helping their child with their SLCN. In addition they reported more consequences of SLCN and of it having a greater impact on the family. These parents had lower expectations of treatment for their child, experienced more barriers to treatment and were less satisfied.

Group differences: Parent confidence in helping their child with SLCN

The sample (baseline $N=199$, follow up $N=148$) was split into two groups based on the median score of 15.5 of confidence to help factor of the FLQ. Group one included participants with scores less than 15.5 (better confidence) (baseline: $n=98$, follow up $n=68$) and group two those with 15.5 or more (baseline: $n=101$ follow up $n=80$). Significant differences between the means of the groups were observed in all four domains under study:

Parent personal circumstances: Parents in group 1 (lower confidence ratings) rated FLQ family impact lower (indicating a greater impact) (Mdn=13) than those in group 2 (Mdn=20) $U=2784$, $Z=-5.34$, $p=.001$ with a small to medium effect size ($r=-.38$).

Parent beliefs (child problem): On average, participants in group 1 endorsed less self-blame causal attributions (Mdn=6) than group 2 (Mdn=7), $U=3445.5$, $Z=-3.70$, $p=.001$ with a small to medium effect size ($r=-.26$).

Parent beliefs (self-efficacy): Participants in group 1 reported higher ratings of overall parenting self-efficacy (SEPTI total) (Mdn=223.5) than those in group 2 (Mdn=209), $U=2865.5$,

$Z=-5.13$, $p=.001$ with a small to medium effect size ($r=-.36$). Their confidence in following SLT recommendations ($Mdn=48$) was also higher than participants in group 2 ($Mdn=43$), $U=3535$, $Z=-3.49$, $p=.001$ with a small to medium effect size ($r=-.25$).

Child characteristics: On average parents rated their child's functional communication skills (FOCUS baseline) higher ($\bar{X}=111.0$) than participants in group 2 ($\bar{X}=89.3$), $t(197)=2.83$, $p=.005$ with a small to medium effect size ($r=.20$). Ratings on the FLQ child communication factor were higher in group 1 (better skills) ($Mdn=6$), than in group 2 ($Mdn=5$), $U=3543$, $Z=-3.49$, $p=.001$, with a small to medium effect size ($r=-.25$). Participants in group 1 rated the FLQ social competence factor as lower (more competent) ($\bar{X}=13.0$) than those in group 2 ($\bar{X}=15.1$), $t(197)=-3.17$, $p=.001$, with a small to medium effect size ($r=.23$). On average the children of participants in group 1 were given fewer SLCN descriptors by SLTherapists ($\bar{X}=1.25$) than those in group 2 ($\bar{X}=1.51$), $t(197)=-3.42$, $p=.001$, with a small to medium effect size ($r=.25$).

Treatment experiences: **Baseline:** Parents in group 1 rated their FLQ treatment experience lower (better view) ($Mdn=6.37$) than those in group 2 ($Mdn=8$), $U=2959.5$, $Z=-4.92$, $p=.001$, with a small to medium effect ($r=-.34$). On average, participants in group 1 rated their expectancies for child improvement (PETS) higher ($\bar{X}=25.4$) than those in group 2 ($\bar{X}=23.2$), $t(197)=4.27$, $p=.001$ with a small to medium effect size ($r=.30$). These participants also, on average, rated their expectancies for parent involvement (PETS) to be higher ($\bar{X}=13.1$) than those in group 2 ($\bar{X}=12.1$), $t(197)=4.14$, $p=.001$, with a small to medium effect size ($r=.28$).

Follow up: Parents in group 1 rated the all aspects of the therapeutic alliance (WAI) higher ($Mdn=81.5$) than those in group 2 ($Mdn=75.5$), total $U=1919.5$, $Z=-3.08$, $p=.002$, with a small to medium effect size ($r=-.25$). Parents in group 1 also reported fewer competing activities/stressors (BTPS) ($Mdn=21$) than those in group 2 ($Mdn=23$), $U=2023.5$, $Z=-2.70$, $p=.01$ with a small to medium effect size ($r=.47$). As well as experiencing fewer treatment issues (BTPS) ($Mdn=8$) than participants in group 2 ($Mdn=9$), $U=2085.5$, $Z=-2.59$, $p=.01$, with a small to medium effect size ($r=-.21$).

In summary, parents in group 1 who showed less confidence in being able to help their child's SLCN at the beginning of the study and who subsequently had higher levels of adherence could be characterised as follows: At baseline their child's SLCN had less impact on the family, parents blamed themselves less and were more confident in their parenting and also in following SLT recommendations. They described their children as having less severe communication difficulties (as indicated by scores on the FOCUS, FLQ communication and

social competence); SLTherapists also used fewer SLCN descriptors for these children. Parents in group 1 also anticipated a better treatment experience (FLQ), expected better outcomes for their child and to be involved more (PETS). At follow up these parents gave higher ratings of the therapeutic alliance, experienced fewer competing activities/stressor and fewer treatment issues.

Group differences: Parent confidence in following SLT recommendations

The sample (baseline N=199, follow up N=148) was split into two groups based on the median score of 46 for parents' confidence in following SLT recommendations (SE-SLTR). Group one included participants with scores less than 46 (baseline: n=98, follow up n=68) and group two those with 46 or more (baseline: n= 101 follow up n=80). Caution is required in interpreting these results as the effect of this predictor within the regression was weak (effect size <.2). Significant differences between the means of the groups were observed in three of domains under study:

Parent beliefs (child problem): Parents in group 1 were less likely to endorse the causal attribution of early medical experience (Mdn=9) than those in group 2 (Mdn =10), $U=3738$, $Z=-2.99$, $p=.003$, with a small to medium effect size ($r=-.21$).

Parent beliefs (self-efficacy): Participants in group 1 rated themselves as having lower parenting self-efficacy in total (Mdn=209) than those in group 2 (Mdn = 221.5), $U=3203.5$, $Z=-4.29$, $p=.001$, with a small to medium effect size ($r=-.30$).

Treatment experiences (follow up): Participants in group 1 rated the bond scale on the WAI as lower (Mdn=22) than those in group 2 (Mdn=24), $U=1887.5$, $Z=-3.23$, $p=.001$, with a small to medium effect size ($r=-.27$). Although no significant differences were found in any other of the subscales in the WAI, parents in group 1 overall rated the therapeutic alliance as lower (Mdn=74) (WAI total) than those in group 2 (Mdn=79.5), $U=1967$, $Z=-2.90$, $p=.004$, with a small to medium effect size ($r=-.24$). Participants in group 1 assigned lower ratings of importance to the recommendations (Mdn=87.5) than those in group 2 (Mdn=93.75), $U=1857.5$, $Z=-3.24$, $p=.001$, with a small to medium effect size ($r=-.27$). Parents in group 1 also reported a greater number of barriers (BTPS total) (Mdn= 6) than those in group 2 (Mdn=3), $U=1788.5$, $Z=-3.60$, $p=.001$, with a small to medium effect size ($r=-.29$). Parents in group 1 rated their initial experience of SLT (CSPQ) as lower (Mdn=16) than those in group 2 (Mdn=17.5), $U=1720.5$, $Z=-$

3.93, $p=.001$, with a small to medium effect size ($r=-.32$). No other domains of the CSPQ reached significance, but overall, parents in group 1 also rated their overall satisfaction with SLT service (CSPQ) lower ($Mdn=72$) than parents in group 2 ($Mdn=77$), $U=1983$, $Z=-2.84$, $p=.004$, with a small to medium effect size ($r=-.23$).

In summary the reported regression model indicated that scores rating confidence in following recommendations were positively associated with adherence but with a small effect size ($<.2$). Parents with lower levels of confidence in following recommendations and subsequently who had lower levels of adherence, can be characterised as being less likely to endorse an early medical experience as a cause of their child's SLCN and more likely to identify themselves as having lower levels of overall parenting self-efficacy. At follow up, these participants gave lower ratings of the relationship between themselves and the SLT (WAI bond), as well as overall rating the therapeutic alliance lower. They also indicated that the recommendations given by the SLTherapist were less important. Parents in group reported more barriers to treatment, rated their early experiences of SLT lower and were overall less satisfied.

Conclusion

This chapter reported the results of Phase 3 of this thesis. The results will be summarised and discussed in the following Chapter.

CHAPTER 10

Discussion: Cohort Study

To the author's knowledge, this exploratory cohort study is the first to investigate parental participation in their young child's SLT and consider how it is related to child outcome. The predictive factors explored in this research represented the domains of *Parent Personal Circumstances*, *Parent Beliefs*, their *Experience of Treatment* and *Child Characteristics*. This study identified the levels of parental attendance and adherence to recommendations made by a SLTherapist. One hundred and ninety nine parents were recruited, and completed a set of seven measures relevant to these domains within four to six weeks of their child's initial assessment with SLT services. One hundred and forty eight parents remained in the study and completed the nine follow up measures between six to eight months later. Multiple regression analyses identified significant predictive factors and relations with child outcome.

The participants in this sample represented a diverse population ethnically, linguistically and economically, and approximately half of the mothers were working. The majority of children were provided with a single description of their difficulty by SLTherapists, with language difficulties being the most frequently reported, followed by speech problems and then dysfluency. Children who were seen primarily for eating and drinking difficulties were excluded. For the majority, SLCN was their only need (79.4%), with the remainder having additional identified diagnoses (20.6%). The ratio of boys to girls was comparable to published data (Law et al., 2000).

Over the period of the research, families were offered an average of nine appointments, three for assessment and six for treatment, with an average of 8-9 recommendations provided by a SLTherapist. Although a range of interventions were offered, the most frequent (71%) was a four week generic Parent Child Interaction group (PCI), offered regardless of child difficulty. Over half the sample was offered a single type of treatment; 29% of the remainder were provided with treatments that crossed classes of intervention e.g. starting with language intervention, followed by speech. Whilst the changes are acceptable from a professional perspective, it is not known how these changes are perceived by parents. A proportion of

families (39.7%) were discharged from the service post follow up, predominantly at parent request (24.6%) but with a proportion (8%) that no longer required treatment.

Parental perceptions of SLCN have not been systematically explored, and within this cohort a range of beliefs were expressed. At the beginning of treatment, parents recognised, on average, twelve symptoms in their child, with the most common being poor speech intelligibility or difficulties in being understood; reduced vocabulary and tantrums. Parents identified an average of six potential causes of their child's SLCN and multiple causes have previously been reported in qualitative studies of parent experience in SLT (e.g. Glogowska, 1998; Kummerer et al., 2007; Marshall et al., 2007).

From an illness perceptions perspective, parents tended to believe their child's SLCN would be of shorter duration, not fluctuating and to have few consequences particularly for themselves. Parents generally believed that they and their child were in control and also that treatment could control their child's SLCN. They also perceived that they held a coherent understanding of their child's problem. There was an overall tendency for parents to experience negative emotions in relation to their child's SLCN, a finding previously observed in qualitative studies of SLT (Glogowska, 1998; Glogowska & Campbell, 2000; Langevin et al., 2010). Parent perceptions in the Illness Perceptions Questionnaire (IPQ) domains of coherence, control and emotions were comparable to parents of older children with autism (Al Anbar et al., 2010) but all other domains were different, with these parents, believing their child's problem to be longer in duration, fluctuating, with greater consequences than those in the present study. The parents in their study also expressed uncertainty that treatment could control their child's problem (Al Anbar et al., 2010). The pattern of beliefs also differed from those observed in parents of adolescents with illnesses e.g. anorexia and insulin dependent diabetes (Sim & Matthews, 2013) and with cystic fibrosis (Beinke et al., 2016). Comparisons could not be made with some studies e.g. parents of children high risk neonatal infants (Brooks et al., 2012) or children receiving physiotherapy (Rabino et al., 2013), because of differences in measures or the unavailability of descriptive statistics for illness perceptions. However, parental perceptions about their child's problem may be heterogeneous relative to condition and child age. In a review of patients perceptions of illness across a range of medical illnesses, heterogeneity of beliefs was observed in fifty percent of included studies (Hagger & Orbell, 2003).

In relation to parents' self-efficacy beliefs, this cohort were generally confident in their parenting skills across all domains, being most confident in nurturing their child and the least

confident in teaching their child and in providing instrumental care routines. Parenting self-efficacy has previously been explored in SLT with one small study with parents (N=25) of children (3-6 years) with SLCN and using a version of the Self-Efficacy Parenting Tasks Index (SEPTI) (Coleman & Karraker, 1998) (Harty et al., 2007). As with the present study, parenting self-efficacy was generally high and highest in the nurturing domain. The lowest mean scores were in the teaching domain, but unlike the present research, also in the discipline domain. The instrumental care domain was not included in their version of the measure. Parents in the present study also appeared to be confident in their ability to carry out SLT recommendations, an area not previously investigated in SLT. Parents' ratings on the Family Life Questionnaire suggested that overall the functioning of the child and family were adequate.

Parents were generally positive about their expectations of SLT but experienced some uncertainty particularly in relation to their own role. Following intervention, parents rated the therapeutic alliance as positive and were predominantly in agreement with therapy goals and activities. Whilst this was also true for the relationship with the SLTherapist, it received the lowest average rating. Parents rated the majority of recommendations as important (88%). Satisfaction with their experience of SLT was positive and comparable with published data in another SLT service (Girolametto et al., 1993), with parents being the most satisfied with their own role in treatment.

10.1 Level of Non-Attendance

Although the number of sessions offered varied, the average level of non-attendance was 25.4% (1767 appointments). A small percentage attended all appointments (18%) with the remainder missing between one and eight sessions. This rate is higher than previously published figures in a comparable cohort, which included rural areas (Broomfield & Dodd, 2004). This figure is also higher than the rate of non-attendance for the whole SLT service from which the cohort is drawn, suggesting higher non-attendance in early-years services. Even when accounting for the method of measurement, service delivery, and child condition, rates of non-attendance are higher in comparison with other paediatric populations (e.g. Curran et al., 2015; Gordon et al., 2010; Mitchell & Selmes, 2007; Samuels et al., 2015; Sherman et al., 2009). However, the total number of appointments offered in the present study was significantly lower than all other studies, which may account for the difference.

10.2 Predictors of Non-attendance

Variables associated with non-attendance were found within three domains: *Parent Personal Circumstances* (5 variables, baseline and follow up), *Parent Beliefs* (3 variables, child illness perception beliefs (2) and self-efficacy) and *Child Characteristics* (1 variable). When the effects of each domain on attendance were investigated separately, a number of factors were found to be significant. In the area of *Personal Circumstances*, the final education level of the mother and maternal age influenced attendance, with older and more educated mothers having fewer missed appointments. A retrospective perception that their child's SLCN had a greater impact on the family e.g. going on an outing, negatively affected attendance. When *Parents' Beliefs*, including illness perceptions and self-efficacy were separately assessed, a belief that their child's problem was fluctuating and caused by an early medical event, such as prematurity, were related to higher attendance. Higher parental confidence in an ability to provide instrumental care (i.e. the provision of routines, sleep habits and eating well) was related to a fewer missed appointments. In the *Child Characteristics* domain, the reporting of more symptoms was associated with higher attendance.

When all domains were assessed collectively (figure 10-1) in a multiple regression analysis, a similar pattern arose. Aspects of parents' personal circumstances and their beliefs were significantly associated with non-attendance providing partial support for the study hypothesis. The influence of ethnic group, impact of SLCN on the family, timeline-cyclical beliefs and experience of competing activities/life stressors were not significant. Poorer attendance was seen in younger mothers who attained lower levels of education, were less confident in providing instrumental care-routines with their child and were more likely to believe an early medical experience caused their child's SLCN. This specific pattern of predictors may be unique to SLT; however, when the variables are considered individually some support can be found within the literature.

Maternal education has been shown to be associated with child health, including SLCN, and education (Greenaway, Leon, & Baker, 2012; Hoff & Tian, 2005; Magnuson, 2007; Paul et al., 2000), although not specifically with attendance at appointments. Educational level is often viewed as a proxy measure for SES along with income and area indices of deprivation. Composite scores of SES (including maternal education) have been shown to be associated with non-attendance in a number of studies (e.g. Carr et al., 2015; Fernandez & Eyberg, 2009; Lavigne et al., 2010). Whilst this literature is potentially supportive of the present findings, it

may depend on the concept being measured as, although ethnicity was included in the present model, the index of area deprivation was not related to non-attendance. The differential effects of such indices have also been previously recognised (Geyer et al., 2006) and how they can act as mediators and moderators of health behaviours (Schüz, 2017).

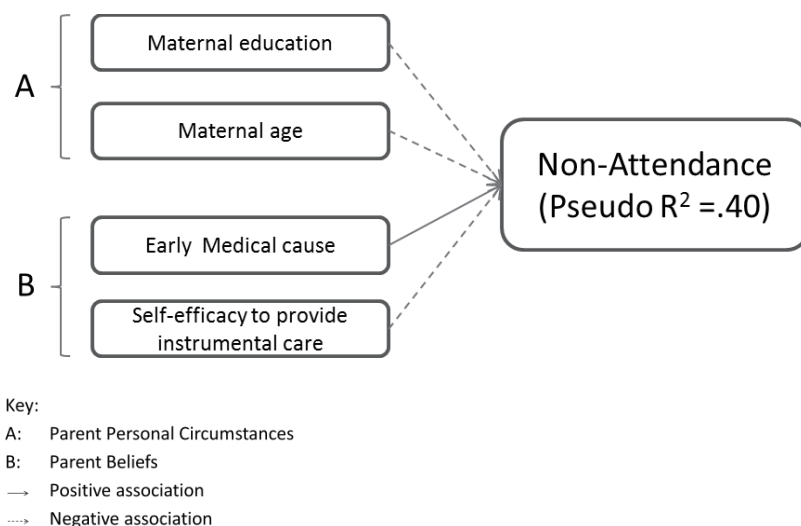


Figure 10-1 Final Model of non-attendance in SLT

The relationship between level of education and health is well known and with typically large effects (Baker, Leon, Smith Greenaway, Collins, & Movit, 2011). Although an overlap with indices of wealth exists, income may only account for approximately a third of the effect (Cutler & Lleras-Muney, 2006). Multiple explanations for this relationship have been proposed including, in lower levels of education, a lack of knowledge about the negative influence of certain behaviours on health and the absence of role models for healthy behaviours. Better education is associated with a greater sense of control and ability to make choices such as healthy behaviours (Pepper and Nuttel 2014). Health literacy may also be an important factor in understanding the relationship between education and health outcomes, as to function within a healthcare environment basic reading and numerical tasks are required. Health literacy has been shown to partially mediate the relationship between education and health outcome in a population of low-income, ethnically diverse patients with diabetes (Schillinger, Barton, Karter, Wang, & Adler, 2006). Another mechanism is where education transforms general intelligence through improving critical thinking skills and decision making abilities allowing for well-reasoned risk assessments and health decisions to be made (Baker et al., 2011; Cutler & Lleras-Muney, 2006). There is some support for the application of this model to maternal education, for example in Ghana and Nepal, studies found that formal education

increased mothers' understanding of the multiple dimensions of health resulting in increased use of health services (Greenaway et al., 2012; Rowe, Thapa, Levine, Levine, & Tuladhar, 2005). It is possible that mothers with lower levels of education in the present study were less able to accurately assess the risks of SLCN for their child in order to make a fully informed decision about attending SLT.

In comparison to mothers with higher levels of education, less educated mothers were more likely to think their child's problem is fluctuating, and experience fewer competing activities or stressors suggesting that they were less concerned about their child. These perceptions may have been clinically inaccurate, lending support to the assertion of an inaccurate assessment of risk. However, since many young children's SLCN does spontaneously resolve (Howell et al., 2010; Law et al., 1998; Law et al., 2000; Stein et al., 2011; Yairi, 2005), they could equally have been correct in their assessment of concern.

No previous research was found to support the finding that the age of a parent is related to attendance. Younger age has been shown to be associated with non-attendance in some studies of adults with rheumatology and alcohol problems (Gudjonsson et al., 2004; Milne et al., 2014) and non-attendance has been associated with older age in other research (Cooper et al., 1999). In the present study younger mothers reported more symptoms, held greater beliefs in child-related causes such as personality, emotional state and lack of experience with other children, and thought their child's problem fluctuated. They also believed that their child's SLCN had fewer consequences for their child and themselves. Thus, although these mothers recognised their child's problem, they believed it was not persistent with few consequences indicating that their level of concern was insufficient to promote full attendance. The nature of their causal attributions may also suggest that they thought the SLT would not resolve their child's difficulties as causal beliefs have been shown to be linked to treatment preference. For example in adult patients (Leventhal et al., 2008) and in parents of children with autism, where stronger hereditary beliefs was associated with attending training programmes rather than other treatments (Al Anbar et al., 2010).

Beliefs in a medically-related cause such as child prematurity and being in hospital for a long time was associated with reduced attendance in the regression model. Parents who held these beliefs endorsed fewer external causes such as diet or eating habits, and were less likely to consider themselves as partly responsible, consistent with their view of a medical cause. They also reported fewer symptoms and believed they were in control of their child's SLCN,

supporting the research suggesting causal beliefs can be associated with treatment preference. The nature of causal beliefs has also been associated with the degree of parental distress, for example internal self-blaming attributions were associated with higher distress in mothers of children (1-2 years) with cleft palate (Nelson et al., 2009). Parental beliefs in an external medical cause in the present research, combined with their perceptions of control and reduced symptom reporting may indicate less distress about their child's problem, and a view that SLT was unnecessary for their child. The lack of any other significant differences in child characteristics with parents who did not endorse a medical cause lends some support to this idea.

The small association found between parental self-efficacy to provide instrumental care routines and non-attendance has not been reported in the literature. Providing structure and routine, managing your child's sleep and ensuring they eat well are fundamental to caring for a young child and, whilst not necessarily related to SLCN, they may be more challenging in the context of developmental delay, ASD and SLCN (Keenan, Wild, McArthur, & Espie, 2007). Research indicates that increased behaviour problems can negatively affect parenting self-efficacy which, in turn, is associated with higher parent distress (Hassall & Rose, 2005).

Parents who lacked confidence in providing instrumental care were also less confident in teaching and disciplining their child and perceived their child's SLCN had a greater impact on the family with greater consequences. They endorsed a greater number of causes and understood their child's difficulties less well. They indicated that their child displayed more externalising behaviour with a greater number of symptoms. As the reporting of multiple causes is associated with a person's attempt to make sense of a problem (Cameron & Moss-Morris, 2004), this could indicate that these parents did not have a coherent understanding of their child's SLCN. Overall, these parents lacked self-efficacy in managing their child's symptoms, lacked understanding and were concerned. It is possible that SLT did not match their perceived needs for their child and themselves, or that their needs may have been too great to be able to cope with the additional demand of attending an appointment. The presence of a greater perceived impact on the family and of reporting more competing activities and life stressors within the overall model also provides additional support for multiple burdens on the family, which has previously been identified as a predictor of non-attendance (Karver et al., 2006; Kazdin et al., 1997; Kazdin, 2000).

10.3 Level of Adherence

In this study the average rate of adherence was seventy four percent. The sample included some parents who described themselves as completely non-adherent but the sample was skewed towards higher levels of adherence. This rate appears comparable to parental rates in other clinical areas for example in behavioural treatments for autism (76%) (Moore & Symons 2009) and in psychological treatment for ADHD (70%) (Dreyer et al., 2010). This may be an over-estimation, which is not uncommon when self-report measures are used (DiMatteo, 2004). The inconsistency of the measurement of adherence has been widely acknowledged and recommended practice is to use both objective and subjective approaches (Haine-Schlagel & Walsh, 2015). However, a discrete objective measure, as used in medication adherence studies, is not feasible when measuring behavioural adherence, particularly when the recommendations are carried out in the home.

10.4 Predictors of Adherence

Univariate analysis showed that fifteen variables were associated with adherence in three domains: *Parents' Personal Circumstances*, *Parent beliefs* (child problem and self-efficacy) and *Treatment experience* (baseline and follow-up). No child-characteristics were associated with adherence. Regression analyses first considered the influence of each domain on adherence. Within the *Parent's Beliefs* domain, greater self-efficacy beliefs were associated with higher rates of adherence, including confidence in being to help their child, confidence in their overall parenting skills and confidence in following SLT recommendations. A greater impact of the child's SLCN on family life along with increasing number of competing activities or life stressors was associated with greater non-adherence (*Parent Personal Circumstances* domain). Within the *Parents Experience of Treatment* domain, higher ratings of the importance given to a recommendation resulted in higher levels of adherence.

When all fifteen factors were assessed in a multiple regression, the overall model was significant explaining fifty six percent of the variance in adherence (figure 10-2). Predictors were within the domains of *Parent Beliefs* and *Treatment Experience* providing partial support for the study hypothesis for adherence. Better adherence was observed in parents who gave higher ratings of the importance of a recommendation and were more confident in helping their child and in following a recommendation.

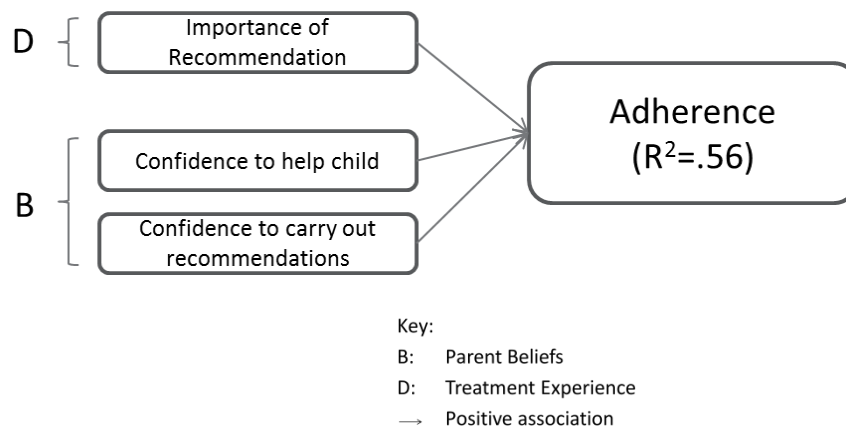


Figure 10-2 Final Model of Adherence in SLT

The importance of a recommendation was also positively associated with parental adherence to recommendations in a study of ADHD; however, this specific factor was not included in their regression model so its relative contribution to their overall model is unknown (Dreyer et al., 2010). Rating a recommendation as important would indicate positive views of the treatment and such views have been shown to support better engagement by parents in treatment (Santer et al., 2014). Relationships between low self-efficacy and failure to carry out health care tasks have been observed both in adults receiving physiotherapy (Jack et al., 2010) and in parents of children receiving psychological and medical treatments (Geffken et al., 2006; Mitchell & Fraser, 2014; Mitchell et al., 2015). Positive beliefs of treatment may be particularly important for parents with low self-efficacy at the beginning of treatment. In a large study of adults receiving treatment for alcohol problems, those with low self-efficacy, but high ratings of therapeutic alliance, fared equally well in terms of outcome as those with high self-efficacy beliefs (Ilgen, Tiet, Finney, & Moos, 2006). Caution is required in the application of this finding to the present research given the difference in populations.

Parents were grouped on the basis of their perspective on these three predictive factors and compared. These comparisons revealed different patterns of beliefs across the groups, but with self-efficacy a common theme. Parents who reported lower ratings of importance of a recommendation also thought their child had more symptoms, had lower confidence in their parenting skills in general, lower confidence in their ability to follow the recommendations and in helping their child with their SLCN. In addition they reported more consequences of SLCN and of it having a greater impact on the family. Lower parental self-efficacy to complete tasks

has been associated with the presence of more child behaviour problems in other clinical populations (Mitchell & Fraser, 2014; Mitchell et al., 2015). However here, despite the presence of increased symptoms and greater impact; it is unclear whether parents are referring to behavioural difficulties. Parents in this group had lower expectations of treatment for their child, experienced more barriers to treatment and were less satisfied. This may be describing parents who, despite their recognition of their child's numerous symptoms and the impact on the family, felt helpless as a result of their own lack of confidence compounded by their expectations that treatment may not help. The literature suggests that self-efficacy is lower in anxious parents or those with low mood (Mitchell & Fraser, 2014; Weaver, Shaw, Dishion, & Wilson, 2008); however, no parental measures of mood were included in the present study. These parents may have been stressed owing to the presence of multiple burdens, which have previously been associated with adherence (MacNaughton & Rodrigue, 2001) and attendance (Kazdin et al., 1997; Kazdin, 1996).

Parents who were less confident in being able to help their child's SLCN also rated their child's SLCN to have less impact on the family; they had fewer self-blaming causal attributions and were more confident in their parenting and following SLT recommendations. They described their children as having less severe communication difficulties across a number of measures and SLT therapists also used fewer SLCN descriptors for these children. They also demonstrated stronger anticipatory beliefs about the expectation and benefits of SLT and, following intervention, gave higher ratings of the therapeutic alliance, suggesting that their expectations and needs had been met. These parents also experienced fewer activities or stressors that clashed with treatment and fewer treatment issues. For these parents lower self-efficacy, present in only one domain of self-efficacy of the three areas measured, may have been a motivating factor to acquire the necessary skills and knowledge to help their child provided by SLT. Research has indicated that lower self-efficacy perceptions are not always associated with poorer performance so the presence of some self-doubt, particularly at the planning stage, may be an incentive (Bandura & Locke, 2003). Treatment expectations were high in this group, including those referring to parent involvement, which may have parallels with outcome efficacy. Positive outcome expectations combined with high perceived self-efficacy can produce greater effects (Iannotti et al., 2006), which may reflect the pattern observed within this group.

Finally, as the regression indicated that confidence in following recommendations was positively associated with adherence, parents with lower levels of confidence in following recommendations were characterised as being less likely to endorse the causal attribution of an early medical experience and more likely to identify themselves as having lower levels of parenting self-efficacy overall. At follow up, participants with this profile gave lower ratings of the relationship between themselves and the SLT, as well as rating the therapeutic alliance lower overall. A poorer alliance, combined with lower self-efficacy can result in poorer treatment outcomes, with the literature proposing that the establishment of a positive alliance is particularly important for individuals with low self-efficacy when entering treatment (Ilgen, et al., 2006). For these parents, a trustworthy clinician, perceived as an expert, may provide the social influence for change (Bordin 1979). Parents, matching this description in the present study, also indicated that the recommendations given by the SLTherapist were less important. They reported more barriers to treatment, rated their early initial experiences of SLT (e.g. referral) lower and were overall less satisfied. Similar relationships have been observed with parents of children with ADHD, whereby poorer ratings of therapeutic alliance were associated a higher number of perceived barriers (Kazdin et al., 2005). Research has also identified a negative relationship between multiple barriers and satisfaction with treatment in community mental health (MH) treatment for children (Salloum, Johnco, Lewin, McBride, & Storch, 2016). It is possible that the needs of these parents and their child were not being met affecting their relationship with SLT and overall satisfaction with their experience.

10.5 Relationships between Attendance, Adherence and Outcome

Non-attendance and adherence were unrelated in this sample. This was unexpected as previous research in parent participation in mental health services has indicated that attendance is related to an increase in adherence (Haine-Schlagel & Walsh, 2015). This discrepancy may be explained by differences in populations and measurement. For example, in one study parent adherence referred to attendance at meetings in school or with professionals rather than homework completion (Richards, Bowers, Lazicki, Krall, & Jacobs, 2008). Given the nature of the SLT interventions offered, it is possible to adhere to recommendations for home practice regardless of attendance. Anecdotally many parents commented that many of the recommendations provided by SLTs were already known to them and that they had already been practising them with their child prior to therapy.

Adherence and attendance were positively associated with child outcome, although, as the effect size for non-attendance was less than the pre-defined study requirements, it was not included in further analyses. The small attendance-outcome relationship may be related to variations in the sessions offered (1-20) to parents within the sample. Parental non-adherence is associated with child outcome in psychological treatments (e.g. Haine-Schlagel & Walsh, 2015; Kling et al., 2010) but, in the present study, adherence did not reach significance in the final child outcome model, as its effects were marginalised by the addition of satisfaction with the SLT service. Adherence and satisfaction are however, closely related, with consistent relationships observed across a wide variety of disease types and study designs (clinic trials/observational studies) in adults (Barbosa et al., 2012). In addition both attendance and adherence were generally high, which may minimise effects.

10.6 Predictors of Child Outcome

Children's scores on the FOCUS (Thomas-Stonell et al., 2010) changed by forty-one points on average following intervention. This is higher than the change recorded in the research validating this measure (average 18 points), although in their study, the children were younger and the change was measured over a 3 month period as compared to on average 8 months in the present research (Thomas-Stonell et al., 2013). Differences in treatment are unknown as it was not described in their research and in the present study multiple interventions were offered. In the present study, not all children benefited from SLT, but a minimally clinically important difference (MCID) demonstrating a positive change was observed in a large proportion of the sample (65%).

Univariate analyses identified a large number of variables that were associated with the FOCUS follow up score, including one in the *Personal Circumstances* domain; seven within the *Parent Beliefs* domain (illness perceptions and self-efficacy), six within the *Child Characteristics* domain; and at follow up five relating to *Treatment Experience*, which included adherence. An additional domain represented treatment data, and items included for example, the number of different types of intervention and the number of intervention sessions offered, with only the former included in the regressions due to not meeting the study requirements for effect sizes. In total, fifteen variables had sufficiently large effect sizes to be included in the multiple regression analyses, which were run to examine the effects of baseline predictors, follow-up variables and finally a combined model.

Exploring the baseline variables, better child outcome was found in children whose communication abilities were rated higher on the FOCUS by their parents at the beginning of the study, whose parents rated them as being more socially competent at this time but with a greater number of symptoms in total, and whose parents believed their child's SLCN was short in duration. The change in child outcome was clinically meaningful (defined as a 16-point change) when both the baseline FOCUS and social competence scores increased by one standard deviation, but similar increases in the other significant factors did not produce meaningful changes in child outcome. Following treatment, better child outcome was found in children whose communication abilities were rated higher on the FOCUS by their parents at the beginning of the study, and whose parents reported greater satisfaction with SLT services. The changes in child outcome that resulted from a one standard deviation increase in satisfaction were not clinically meaningful.

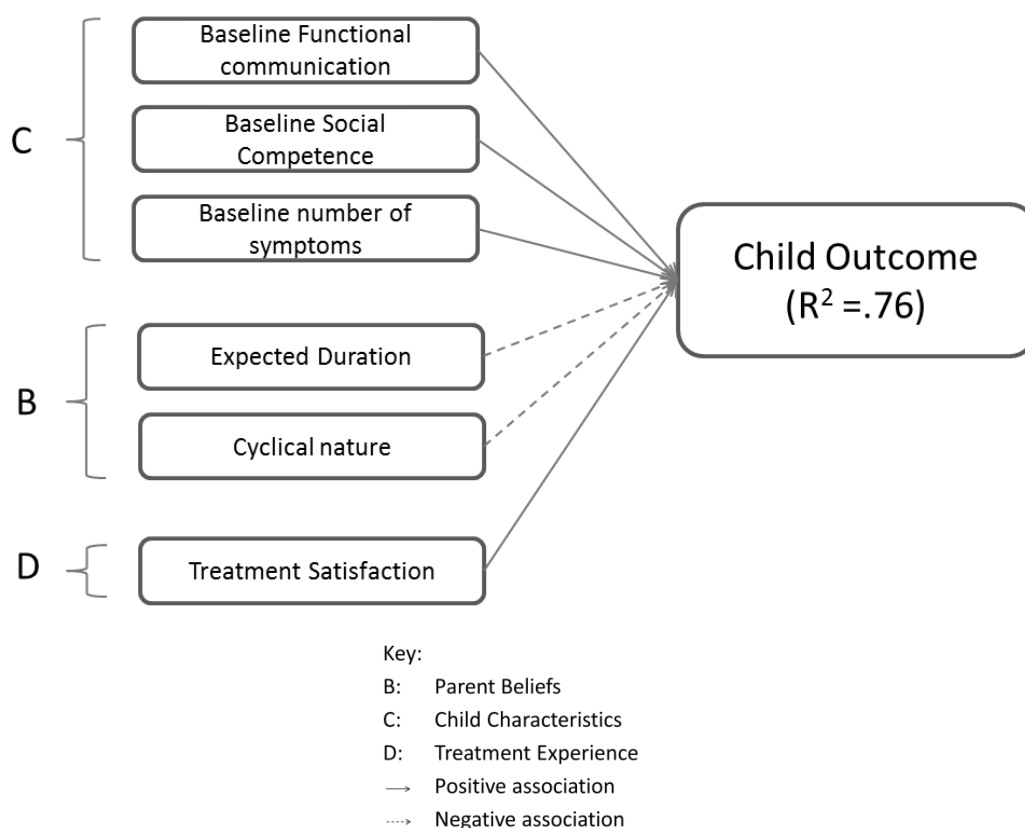


Figure 10-3 Final Model of Child Outcome in SLT

When both baseline and follow up variables were combined into an overall multiple regression (figure 10-3), the children who changed the most were those with better functional communication skills at the start, who were rated as more socially competent. And, although the parents of these children identified a greater number of symptoms in them, they believed

their child's SLCN was short in duration and constant rather than fluctuating. They also reported greater satisfaction with SLT services. Collectively this model explained a large proportion of the variance (76%) in the original data. A one standard deviation increase in the baseline FOCUS score resulted in a clinically important outcome (defined as a 16-point increase) and this was almost the case for the social competence of the child (15-point increase) but not for any other variable.

This suggests that the children who benefited most from SLT were those who were more able but whose parents recognised symptoms that may warrant intervention. It is possible that these children's difficulties were transient as it is known that a significant proportion (actual rates vary dependant on the type of SLCN) of younger children with SLCN will resolve spontaneously (Howell et al., 2010; Law et al., 1998, 2000; Stein et al., 2011; Yairi, 2005). Severity of SLCN is not always indicative of a persisting condition (Bishop et al., 2003). However, social competence does seem predictive, with poorer social competence being a core feature of ASD which may require more intensive interventions (e.g. Pickles et al., 2016). As almost twelve per cent of the sample had confirmed diagnoses of ASD, it would be have been beneficial to evaluate the influence of this group in particular. The percentage of those with undiagnosed ASD in the sample is not known, although a larger proportion (23%, including ASD) of children were described by SLTherapist as having social communication difficulties in addition to other SLCN.

Treatment data did not reach significance in the model, although the number of types of intervention offered was included. The number of intervention appointments offered was positively associated with child outcome but with very small effect sizes and with a large variation in number. Intervention sessions in this SLT service are typically 30-45 minutes long (personal communication) indicating that children in the present study received on average 3-4.5 hours of treatment over a period of eight months. The commonest type of intervention was a four week generic Parent-Child-Interaction (PCI) group (71%) in which the attention given to a specific child is shared. This may indicate that, on its own, this group was unlikely to achieve a MCID in a child. An average of six hours of community based SLT intervention for pre-school children with SLCN over a period of eight months has previously been shown to be ineffective (Glogowska, Roulstone, Enderby, & Peters, 2000). Participants in Glogowska and colleagues' (2000) UK study were comparable to the present research in age and demographics; however, comparisons of child problem were not possible due to the absence of standardised testing in the present study. It is perhaps unsurprising therefore, that

treatment variables were not significant predictors of outcome. Treatment variables and parental adherence were both non-significant but contributory factors in the final model consistent with previous research which has demonstrated the added value of parental contributions in child SLCN treatment (Hampton & Kaiser 2016).

10.7 Limitations

The findings of this study are novel and represent an under-researched area in SLT, but the limitations of the study must be taken into account when interpreting the results.

Recruitment, Sample size, attrition and missing data: One hundred and ninety nine participants were recruited over the course of nineteen months giving a recruitment rate of thirty four percent. The low recruitment rate may call into question the representativeness of this sample as a seventy percent response rate is usually considered necessary (Patel et al 2003). This problem is not unique and involving participants who are most likely to be the most non-adherent is cited as a common challenge in adherence research (Haine-Schlagel & Walsh, 2015).

The follow up sample size was smaller than expected following an attrition rate of twenty six per cent which resulted in a reduction in statistical power for the regression analyses predicting adherence and child outcome. Loss of power has the potential to reduce the precision of parameter estimates and predicted values meaning that statistically significant effects, if present, would be difficult to detect. Where possible, the total scores of a scale were used rather than subscales in order to reduce the number of variables entered into a regression. A post hoc assessment of power indicated that a sample size of 145 would be sufficient for conducting a multiple regression analysis using up to twelve predictor variables; however, the final models of both the adherence and child outcome regressions included fifteen and fourteen variable respectively. The actual sample size was sufficient to detect changes in R squared greater than 7% (Field 2009). The results are interpreted with the knowledge of an increased risk of accepting a null hypothesis when it is false (a Type 2 error). This may be particularly pertinent to the failure to find any adherence-attendance relationship. The generalisation of the results of the adherence and child outcome regressions to other SLCN populations are therefore cautiously applied.

Data were missing due to participant attrition and non-adherence to the study protocol by SLTherapists. A sensitivity analysis was conducted comparing parents who dropped out after completing the first measures and those who completed the study across all available data. Significant differences were observed in three areas, with small to medium effect sizes: participants who had dropped out were more likely to have been discharged from SLT, have more missed appointments and more likely to endorse a greater belief that their child had some control over their communication impairment. There were no discernible differences in reasons for discharge. It was reasonable that parents should decline to continue their participation in a research study about SLT when they were no longer involved with SLT. Believing your child has control of their problem may have reflected optimism for the future impact of their child's SLCN following discharge. Power was therefore reduced when the effects of follow-up factors on non-attendance were evaluated and caution is required when interpreting the results. The listwise deletion approach was used for the management of data.

A second sensitivity analysis, evaluating SLTherapist completed measures, was conducted comparing participants with a completed GAS outcome with those without. This revealed significant differences between groups, and a decision made to omit this measure from any analyses. Although an alternative treatment outcome measure was not available, parent-rated measure of child outcome was used instead. A decision was also made to exclude SLTherapist rated measures of a child's SLCN due to the low return rate. This resulted in a lack of objective measurement of child severity. The inclusion of such objective measurement may have enhanced the quality of the study findings, although perceived severity may be of greater importance in relation to adherence than objective indicators of severity (DiMatteo, 2004; Geffken et al., 2006).

The combination of these effects would suggest that both attendance and adherence were overestimated in this study, and in common with other adherence research (WHO 2003), it is not unreasonable to estimate non-participation rates of thirty to fifty percent.

Potential sources of Bias: Potential sources of bias were minimised where possible (see Chapter 8, section 8.5), including response and item bias. Measurement context effects were minimised by the temporal separation of the baseline and follow up measures; but, for scales reflecting the Treatment Experience Domain, this remained a problem. The effects have the potential to produce spurious correlations between predictor and outcome variables due to the effects of response and contextual bias (Podsakoff et al., 2003). This is particularly

pertinent to the finding that parent-ratings of the importance of a recommendation are a significant predictor of adherence, as the rating immediately precedes the adherence question. Although this finding is clinically plausible, its large effect size may be over-estimated.

Scale Reliability: Factor analyses of both the identity and cause domains of the IPQR-SLCN suggested a number of unidimensional factors; however, some subscales had questionable levels of internal consistency. This may have been due to too few items within the subscale or that they related less well to each other. It is fairly common in patient-generated measures such as these for factor analysis to produce less than adequate results (Eiser & Morse, 2001). When interpreting the results of the analyses caution should be applied to the implications of results associated with these variables from the IPQR-SLCN: Identity scale: externalising behaviours and Cause scale: Child-related.

Simultaneous testing of hypotheses: Within the study multiple hypotheses were tested simultaneously which has the potential to result in familywise error i.e. an inflated Type 1 error rate (incorrect rejection of the null hypothesis). A post-hoc analysis using the Bonferroni method was considered, but this method is also considered too conservative (Noble, 2009). In addition, reducing the risk of type 1 errors increases the risk of type 2 errors (Perneger, 1998), and for an exploratory study such as this it was considered justifiable to accept an inflated Type 1 error rate. Acceptable effect sizes were adjusted, but any significant findings would need replication.

Measurement of Variables: The selection of measures will be considered in the overall discussion (Chapter 11). Specific challenges observed within the present study are presented here. All measures included within the study were parent-rated, including two of the main outcome measures: adherence and child outcome. This risks overestimation of measured variables and inaccurate recall and self-presentation bias may affect the validity of data (DiMatteo, Giordani, Lepper, & Croghan, 2002). For adherence, triangulation of measurement is recommended, with the addition of clinician-rated scales and objective measures to improve reliability and validity (Shaw, Williams, & Chipchase, 2005); however, as all were parent-rated (except attendance) the relative effects of variables may still be interpretable. Whilst the introduction of objective scales may have enhanced the study in some areas, this could also be a limitation given the low concordance between self-report measures and objective scales (Garber et al., 2004).

When measuring therapeutic alliance (TA), it is best practice to obtain multiple perspectives of the alliance and to take measurement on multiple occasions during an intervention to account for the dynamic nature of the alliance and its differential effects at different stages of treatment (Elvins & Green 2008). In the present study, TA was measured at a single time point and by parents only to reduce the burden on participants and SLTherapists. However, as other studies have indicated that TA is stable between one to six months (Hawley & Garland 2008) interpretations may have validity. Parents in this study also worked with an average two SLTherapists. This would indicate that the judgement of TA represented a summary of participants experience throughout treatment with multiple clinicians, reducing its specificity in comparison to other studies of TA. As a result the effects of TA may be underestimated in the present study.

Use of ‘median split’ post hoc analyses: The use of this technique risks reduced power, loss of individual variation (Rucker et al., 2105) and makes an assumption of linearity (Gelman & Park, 2008) thus limiting the validity of the interpretations. Whilst the intention for using this technique was for additional interpretation of findings rather than inference, the findings should be interpreted cautiously. An alternative method, where statistical power is not a concern, would have been to split groups into three parts based on tertiles or upper and lower quartiles (Gelman & Park 2008). This provides the same ease of interpretation as the median split but without such loss of power and allows for consideration of non-linearities (e.g. the effect of a trait on an outcome occurs only for those 'high' on the scale not 'low' to 'average').

10.8 Future directions: clinical and research implications

The results of this study indicate that SLTherapists should be aware that younger parents who are less educated, with specific medical related causal beliefs and lower self-efficacy in providing basic care routines may be at greater risk of missing appointments. When parents were grouped and compared based on these four factors, the pattern of beliefs for three of the factors suggested a lack of concern about their child, or reduced parental distress, in contrast to the fourth, which appeared to reflect parents with high levels of both, as well as low self-efficacy. Demographic factors are unmodifiable by treatment; but, it may be possible to influence parents’ beliefs or understanding of the long term risk of SLCN through psychoeducation. Exploring parents’ views about their child’s problem at the start of

treatment may well be a worthwhile investment in enhancing attendance. However, this may be dependent on further research as, although non-attendance was associated with child outcome, its effect size was small. Future research could consider how psychoeducation for a targeted group of younger parents with lower education levels effects non-attendance.

Parents' views of a particular treatment recommendation, their confidence in following it and in helping their child, are important in understanding parental adherence to the SLT treatment provided in this study. A significant proportion of the therapy offered to this cohort focused on teaching parents how to modify their communication and interaction style, as well as the environment. What is not yet known is whether the role of self-efficacy in this cohort was specific to this type of intervention or indeed if self-efficacy changed as a result of intervention. Future research could consider the role of parents' self-efficacy in adherence across treatment types and examine potential mediating and treatment effects on child outcome. Research should also consider the influence of parent-reported barriers to following specific recommendations. This variable may be important, but was not fully explored in this study due to the large number of recommendations requiring qualitative analysis. Differences in the mean adherence ratings were observed when a sub sample of recommendations were examined.

The main predictors of child outcome were the communicative and social competence of the child, but with parent recognition of a higher number of child symptoms; parent beliefs about the duration and persistence of the problem, and their satisfaction with treatment; attendance, adherence and treatment variables did not predict outcome. This may be related to the duration or type of treatment offered. It may also describe children whose difficulties were likely to spontaneously resolve. Thirty percent of the children did not demonstrate clinically meaningful change; however, the lack of objective child data meant that this group could not be explored further. Equally, for those where changes were meaningful, it is unclear what proportion continues to have clinically significant difficulties. In Glogowska and colleagues (2000) research, seventy percent continued to have difficulties warranting intervention. Future studies should include standardised assessment of a child's SLCN, at baseline and follow-up and where appropriate clear diagnoses of SLCN provided. Methods of identifying persistent SLCN should be included. Treatment should involve a greater number of hours, which in a community sample may necessitate a longer follow-up period due to service demands. Subgroups of SLCN should be examined but with a groups of comparable size and a sufficiently large sample.

Future research may wish to examine adherence to treatments in school-aged children and incorporate fidelity to treatment protocols. In this population, interventions are typically delivered in the school setting and supported by SLT assistants and/or teaching assistants and teachers, with parent involvement diminished. Recent research however, indicated that a manualised intervention delivered by SLTherapists or SLT Assistants (regularly monitored by SLTherapists) results in better outcome for children than the same intervention delivered by school staff (McCartney, Boyle, Ellis, Bannatyne, & Turnbull, 2015). This RCT with children (6-11 years, N=69) attempted to measure adherence and treatment fidelity to the manualised treatment and, although the data received was incomplete, concluded that treatment fidelity, adherence and dosage may explain lack of progress in the school staff delivered intervention.

Conclusion

This research has provided preliminary evidence of the influence of parents' personal circumstances, beliefs about their child's problem, personal self-efficacy and experience of their child's treatment on participation in their child's therapy, with some supportive evidence from the literature. Levels of participation were generally high in this South London cohort but may be over-estimated due to recruitment difficulties and attrition, and for adherence, due to measurement issues. Attendance and adherence were unrelated and the specific variables that predicted them differed. Non-attendance was greater in younger, less-educated mothers, and who held stronger beliefs that their child's problem was caused by an early medical experience and who were less confident in their ability to provide instrumental care routines for their child. Parents appeared to be less concerned and perceived SLT as unnecessary; or were concerned, perhaps overwhelmed, and considered that SLT was not meeting their needs. With the proposal that education may enhance higher order thinking, it is possible that these parents' attributions about their child's SLCN were inaccurate, somewhat supported by the absence of significant differences between child variables. Although not measured in this study, health literacy may be a mediating factor between education levels and attendance.

Greater levels of adherence were observed in parents with strong endorsements of the importance of recommendations and who held higher self-efficacy beliefs in their ability to help their child and follow the recommendations. Tentative characterisations suggest that parents with lower levels of adherence may have been stressed due to the impact of their

child's problems, lack of confidence in themselves and multiple burdens, and appeared to have less faith that treatment could help. Others were perhaps less stressed but had lower levels of parenting self-efficacy and perceived that treatment was also not meeting their needs and resulted in reduced satisfaction. Self-efficacy was potentially a motivating factor for adherence in other parents when it occurred in one domain only (i.e. self-efficacy to follow recommendations not parenting self-efficacy or self-efficacy to help) and when expectations of treatment were higher. Self-efficacy and treatment beliefs appeared to be important underlying factors.

The majority of children demonstrated clinically meaningful changes in their functional communication at follow up, but it is not known how many continue to present with SLCN that warrants intervention. Factors predicting child outcome were located in the domains of *Child Characteristics*, *Parent Beliefs* and *Treatment Experiences*. Participation was not a significant factor in the model predicting child outcome, neither were any treatment data. The children with the best outcomes were those whose functional speech and language skills were better at the start, who were more socially competent, and had parents who identified more symptoms, and believed that their child's SLCN was stable but shorter in duration. Children in this study however, typically received only a small amount of intervention and, in the absence of objective measures of child characteristics it was not possible confirm if these children could be considered as having a SLCN that would resolve spontaneously. Predictors of outcome may differ with interventions that are longer in duration and in children with objectively confirmed SLCN.

Limitations apply to all analyses, for example, issues of power, bias and reliability of measurement and indicating that these results should be interpreted cautiously. Nonetheless, SLTherapists should be aware of these potential factors and the need to explore parental perceptions of their child's SLCN before embarking on treatment. Future research should include replication of these results accounting for the limitations in the present study. Exploring adherence in particular types of SLCN may be important and in higher dosage interventions. Research could also be extended to other professionals delivering of interventions such as educational staff in school who are significant contributors in the treatment of school aged children with SLCN.

CHAPTER 11

Thesis Summary and Overall Discussion

This thesis explored factors associated with parental participation in SLT and relationships with child outcome. Following a review of the literature (Chapter 1-3) three empirical studies were conducted and discussed. The first phase explored parental experience of SLT with two groups of participants, differentiated by their levels of attendance and analysed using the Framework approach (Ritchie & Lewis 2003) (Chapter 5). This study provided tentative support for the relevance of specific theories and factors in understanding parental adherence in SLT. It informed the selection of suitable measures of these factors and adaptation of the illness perception questionnaire (Chapter 6). The second empirical study piloted the main outcome measures (Chapter 7) which, informed by their psychometric properties and participants' acceptability were included in the main study. This phase also evaluated a recruitment strategy. Phase three (Chapters 8-10) was the main quantitative study involving 199 participants; data were analysed using descriptive statistics (aim 1), correlational and regression analyses (aims 2-5). The aims of this phase are below:

1. To identify levels of attendance at SLT sessions and parental adherence to treatment recommendations in an urban Community SLT service.
2. To determine the extent to which parental factors such as beliefs (illness perceptions, self-efficacy, expectations of treatment), experience of treatment (therapeutic alliance, satisfaction) and personal circumstances (family functioning, SES, practical barriers) relate to parent participation.
3. To determine the extent to which child characteristics relate to parent participation.
4. To identify whether attendance and adherence are related to child outcome following treatment.
5. To determine the extent to which parental factors such as beliefs, experience of treatment, personal circumstances and actual treatment relate to child outcome.

A summary of the results, strengths, limitations, and implications of each study are presented here. An overall discussion follows, including comments on design, application of theories and collective limitations. Future research and clinical implications are discussed, concluding with comments on the wider implications of this thesis for the SLT profession.

11.1 Summary of Empirical Studies

11.1.1 Phase 1: A qualitative study exploring parental experience of SLT in young children (Chapter 5).

Main Findings

- The differences between groups suggested that maternal education, parental recognition of their child's SLCN, a perception of severe child difficulties and active referral-seeking may be associated with increased attendance. In addition, parental beliefs in their own role as being part of the cause and the solution to their child's SLCN and positive treatment beliefs may be linked to increased attendance. Finally, a degree of self-doubt about parenting skills may be a motivate participation.
- Parents can be active problem solvers when approaching their child's difficulties, they make decisions about their child's problem such as to attend or not, and are not passive recipients of therapy.
- The pattern of parent responses indicated that theoretical models associated with participation Self-Regulation Model (SRM), Social Cognitive Theory (SCT), Therapeutic Alliance (TA), Barriers to Treatment Model (BTP)– see Chapter 3) were relevant to SLT.
- Evaluation of factors predicting parental participation should include information about the personal circumstances of parents including demographic data; parents' beliefs about their child's problem, parents' self-efficacy beliefs relating to parenting and following SLT recommendations, and their experiences in treatment.

Strengths

- To the authors knowledge this is the first qualitative study to explore the differences in parents' beliefs and experience of SLT between parents who attended treatment consistently and those who did not.

Limitations

- The qualitative methodology limits the generalisability of the results. However, the data is consistent with other research in SLT, conferring some validity to the data.

- Researcher subjectivity is a major limitation, although efforts were made to challenge any preconceptions by looking for competing conclusions, and to increase reliability through an external researcher validating codes. Supervision was provided by an academic (Dr E. Grunfeld) with extensive experience in qualitative research to account for the inexperience of the researcher.
- Although themes were compared and contrasted, it is not certain that they represent single constructs, making direct comparisons problematic.
- The final limitation is uncertainty over whether data saturation was reached.

Future directions: clinical and research implications

- This research incorporated a descriptive review of existing parent experience literature in SLT, synthesised according to the theoretical basis for this thesis. This approach may be beneficial for interpreting parent experience in future studies.
- This research provided evidence for the relevance of specific factors associated with non-attendance to be used as a basis for a quantitative evaluation of parent participation.

11.1.2 Phase 2: A pilot study to identify appropriate measures of adherence, satisfaction and self-efficacy & illness perceptions.

Main Findings

- The following measures were identified as reliable and appropriate for use in the main study: adherence: MATIF, satisfaction: CSPQ; self-efficacy: SE-SLT, and beliefs about SLCN: IPQR-SLCN.
- The SE-SLT, measuring self-efficacy to follow SLTherapist recommendations, was developed specifically for this study. It demonstrated excellent internal consistency and was acceptable to parents.
- Adaptations to the Illness Perceptions Questionnaire-Revised (IPQ-R) for SLT were acceptable to parents and an evaluation of parent responses indicated that symptoms and causal attributions were representative of their beliefs, providing sampling validity. Following evaluation, additional statements relating to *SLTherapist control* beliefs were removed from the *Views* section.

- Review of the process issues in phases 1 & 2 indicated that recruitment may be improved by increasing engagement with SLTherapists, using motivational and reminder emails and minimising their responsibilities where possible. Primary responsibility for recruitment should be with a researcher. Within a diverse sample, the effect of literacy difficulties on questionnaire completion should be addressed.

Strengths

- This study has made available acceptable measures of adherence, illness perceptions and self-efficacy to follow clinical recommendations for use in SLT.
- Preliminary reliability and concurrent validity was provided for a previously psychometrically untested measure of treatment satisfaction, which may be of future benefit to SLT.

Limitations

- Evaluation of the reliability of the measures is limited due to a lower than anticipated sample size. A larger sample would have permitted the use of confirmatory factor analyses.
- Participants' evaluation of questionnaires, in terms of ease of completion, understanding and time to complete, may have been artificially high due to a highly selective cohort and who were most certainly more adherent than a general population sample.
- The recommendations for the recruitment strategy were based on a small sample; however, the feedback accorded with published recommendations for recruitment and provided an insight into the experiences of SLTherapists.

Future directions: clinical and research implications

- Future studies should undertake an analysis of the factor structure of the identity and cause scales of the adapted illness perceptions measure (IPQR-SLCN) and the satisfaction measure (CSPQ).

11.1.3 Phase 3: Cohort study: identifying the levels and predictors of parental participation in SLT treatments in young children with SLCN, including relations with child outcome.

Main Findings

Parent Beliefs

- Parents' overall perceptions of their child's SLCN can be summarised as follows:
 - *Identity*: an average of twelve symptoms was reported (range 1-26).
 - *Timeline*: a belief in a shorter duration and not cyclical was typical
 - *Consequences* were few.
 - *Control*: parents generally believed that they and their child were in control of the SLCN
 - *Treatment Control*: a general belief that treatment could control their child's SLCN.
 - *Coherence*: parents generally agreed that they held a coherent understanding of their child's problem.
 - *Emotional Representations*: an overall tendency to experience negative emotions in relation to their child's SLCN
 - *Causal Attributions*: generally multiple causes endorsed, with only one parent indicating none. Overall, parents attributed external causes over self-blame, early medical experiences or child-related causes.
- This cohort was generally confident in their parenting skills, in helping their child and following recommendations.
- Parents were overall positive in their expectations of SLT but with some uncertainty in relation to their own role.

Non-Attendance

- Across the sample the rate of non-attendance was 25.4%; parents missed on average two appointments (range 0-8).
- Predictors of non-attendance were from the *Parents Personal Circumstances* and *Parent Beliefs* domains (overall model explained 40% of the variance when using McFaddon's pseudo R^2):
 - Lower final maternal education level.
 - Younger mothers.

- Participants who were less confident in providing instrumental care-routines with their child.
- Participants who were more likely to believe an early medical experience caused their child's SLCN.
- Post-hoc analyses, when characterising parents according to lower ratings of each predictive factor, suggested that parents were either overall less concerned and perceived SLT as unnecessary, or were concerned, but perhaps overwhelmed, and with their needs unmet by SLT. If it is to be believed that education enhances higher order thinking, these parents' attributions may have been inaccurate; the absence of significant differences between child variables provided support for this assertion.

Adherence

- The average rate of adherence was 74%.
- Predictors of adherence were from the *Treatment Experience* and *Parent Beliefs* domains (overall model explained 56% of the variance):
 - Greater belief in the importance of a recommendation at follow up
 - higher self-efficacy beliefs to help their child at baseline
 - Higher self-efficacy beliefs to follow a SLT recommendation at baseline.
- Post-hoc analyses, characterising parents according to lower ratings of each predictive factor suggested that some parents may have been stressed due to the impact of their child's problems, lack of confidence in themselves and multiple burdens, and appeared to have less faith that treatment could help. Others were perhaps less stressed but had lower levels of parenting self-efficacy, treatment was not meeting their needs and resulted in reduced satisfaction. Self-efficacy was potentially a motivating factor for adherence in some parents when it occurred in one domain only and when expectations of treatment were higher. Self-efficacy and treatment beliefs appeared to be important underlying factors.

Relationships between non-attendance, adherence and child outcome

- Non-attendance and adherence were unrelated within this sample.
- Adherence and attendance were positively associated with child outcome, although as the effect size for non-attendance was less than the pre-defined study requirements it was not included in further analyses.

- Adherence did not reach significance in the final child-outcome model, as its effects were marginalised with the addition of satisfaction with the SLT service.

Child Outcome

- At follow up, children's scores on the parent-rated FOCUS (Thomas-Stonell et al 2009) changed by an average of forty-one points. Not all children benefited from SLT, with a proportion rated lower at follow-up (13%). A minimally clinically important difference (16 points) was observed in 71% of the sample but included 5% who were rated lower post treatment.
- Predictors of better child outcome were from the domains of *Child Characteristics*, *Parent Beliefs* and *Treatment Experience* (overall model explained 76% of the variance):
 - higher baseline scores on the FOCUS
 - higher parent ratings of child social competence
 - higher total number of symptoms.
 - beliefs that the SLCN will be shorter in duration
 - beliefs that the SLCN is not cyclical in nature
 - higher ratings of parents satisfaction with SLT

Strengths

- The innovative use Leventhal's SRM to describe parents' perceptions of their child's SLCN within SLT.
- The first very thorough evaluation in SLT of factors associated with non-attendance and adherence in this population.
- The sample is ethnically, linguistically and economically diverse and therefore representing a broad range of perspectives.
- As applied research, drawn from a community sample, it has the potential to support SLTherapists in their clinical practice.

Limitations

- As a result of attrition the follow up sample size was smaller than anticipated and the statistical power for multiple regressions predicting adherence and child outcome were reduced. The actual sample size was ultimately sufficient to detect changes in R squared

greater than 7% (Field 2009). There is an increased risk of a Type 2 error, which may be pertinent to the failure to find any adherence-attendance relationship.

- Caution is required when interpreting the effects of factors assessed at follow-up on non-attendance as a sensitivity analysis, comparing participant drop-out following baseline assessments, identified significant differences between groups on three variables. This included increased non-attendance within the drop-out group. The listwise deletion approach was used for the management of missing data and the potential reduction in power was acknowledged.
- Non-adherence to the study protocol by SLTherapists resulted in missing data. A sensitivity analysis compared participants with a completed GAS outcome from with those without, identifying significant differences. The measure was subsequently omitted from analyses. An alternative treatment outcome measure was not available so a parent-rated measure of child outcome was used. SLTherapist-rated measures of a child's SLCN were excluded due to the low return rate, resulting in a lack of any objective measurement of child severity.
- Measurement context effects were minimised by the temporal separation of the baseline and follow up measures. This could not be avoided for scales reflecting the *Treatment Experience Domain* which included parent-ratings of the importance of a recommendation. Effect sizes may therefore be over-estimated.
- Following factor analysis, two domains from the IPQR-SLCN: Identity scale: externalising behaviours and Cause scale: Child-related, had questionable levels of internal consistency. Caution is required when interpreting any results of the analyses associated with these factors.
- Within the study, multiple hypotheses were tested simultaneously which has the potential to result in familywise error. It was considered justifiable to accept this inflated Type 1 error rate in an exploratory study. Acceptable effect sizes were adjusted, but any significant findings would need replication.
- The use of self-rated measures may affect the validity of data with the risks of overestimation of measured variables, inaccurate recall and self-presentation bias.
- Using multiple data sources (i.e. responders) is recommended practice for the measurement of adherence and Therapeutic Alliance (TA) to improve reliability and validity; however, only one source for each was used. The inclusion of objective scales and multiple informants may have enhanced the quality of the research.
- The effects of TA may be underestimated as in this study measurement was confined to a summary judgement of TA.

Future directions: clinical and research implications

- SLTherapists should be aware that parents' beliefs about their child, personal circumstances and experience of treatment may influence participation.
- Exploring parents' views about their child's problem at the start of treatment may be a worthwhile investment in enhancing participation. However, this finding should be validated by research, as the relationships between participation and child outcome were small and neither were predictive.
- Future research could develop and test a SLCN psychoeducation intervention for a targeted group of younger parents with lower education levels, evaluating its effects on non-attendance in SLT.
- The role of parent-reported barriers to following a specific recommendation should be considered in future studies of adherence in SLT.
- Future research could consider the role of parents' self-efficacy in adherence across treatment types and examine potential effects on child outcome. The effect treatment has on parental self-efficacy beliefs should also be explored.
- For replication, future studies should include objective measures of SLCN to provide indices of severity and outcome. Methods of identifying the risks of persistent SLCN should be included. Treatment should involve a greater number of hours. A focus on participation across different subgroups of SLCN would be welcome.

11.2 Discussion

The empirical studies collectively demonstrate the complexity involved in understanding non-participation in SLT. In this thesis, limitations notwithstanding, multiple factors were identified representing a number of domains. The qualitative study was valuable in identifying areas of potential importance in the study of participation. Some findings were supportive of the results of the main study such as the relationship between maternal education and attendance, the role of causal beliefs (although perhaps not in the direction originally thought), of perceptions of child severity and of treatment satisfaction, and the idea that a degree of self-doubt may motivate participation.

Not all findings coalesced. This may be due to the qualitative paradigm which suggests that rare and common phenomena should be given equal standing (Ritchie & Lewis 2003) but when subsequently assessed quantitatively, their rarity was confirmed. Equally this may have been due to the difference in focus between the two studies; in contrast to Phase 3, Phase 1 was focused on differences in attendance, and included participants whose children were offered SLT in the past 12 months rather than being new to SLT. Differences may due to timing as predictors of non-attendance can differ depending on when participants discontinue treatment e.g. early or late in the process (Kazdin & Mazurick, 1994). Attendance and adherence were also unrelated in the main study and the predictors differed. This may indicate that a further qualitative study, exploring parental experiences based on adherence-rates, may be warranted and future research could explore the predictors of participation at different stages of a patients journey.

The results of both these studies have been discussed at length (Chapters 5 and 10). This discussion will focus instead on the study design, including choice of measures and the involvement of local clinicians in research. The relevance of self-regulation and other theories to SLT will be reviewed.

11.2.1 Design

Measures: The majority of measures used in this thesis, but which were selected on the basis of evidence and good reasoning, had not previously been used in SLT or with parents of children with SLCN (Chapter 6). Psychometric evaluations in the pilot (Chapter 7) and in the main study (Chapter 9) confirmed reliability and sampling validity in this population resulting in a set of measures of potential future benefit for further research in SLT, and not exclusively for the study of participation.

However, for the measurement of TA and parenting self-efficacy two alternative measures which may have been more suitable were discovered after the study started. The psychometric properties of Therapeutic Alliance Scale for Caregivers and Parents (TASCP) (Accurso et al., 2013) were explored in a large study (N=209) with parents of children (4-12 years) attending an outpatient mental health clinic for behaviour problems; it was confirmed as a reliable and valid measure of TA. In contrast to the WAI-S (Tracey & Kokotovic, 1989), it was designed specifically for parents/carers and would not therefore have required modifications. An alternative measure of parenting self-efficacy was referenced (Bloomfield & Kendall, 2007) but

the measure itself was not named and was only subsequently located. This measure, Tool to measure Parenting Self-Efficacy (TOPSE), developed and validated in a UK population, may also have been suitable.

Involving SLTherapists: In the present thesis, every effort was made to ensure clinicians adhered to the study protocol and maintained motivation. Disappointingly, this was only effective for a proportion given the low return rate of SLTherapist-rated measures. Key to the success of future research in community SLT is the support and involvement of SLTherapists in recruitment, treatment and child assessment. A survey of departmental SLTherapists (N=39, n=27 who were involved in the research) (appendix 11) indicated that some therapists were uncertain about the requirements of the study or where to find information. Some lacked confidence to assist in this research and approximately 50% were not motivated. Despite this the majority stated that research was important for the profession. Over the course of the research, changes in staff, including staff turnover, combined with the effects of a significant service redesign, were challenging. Future research should account for service limitations, including staff engagement, in its design. It would be of great benefit for all NHS staff to receive training on research engagement i.e. Good Clinical Practice (GCP) training (www.nihr.ac.uk).

11.2.2 Theoretical application

A number of theories were introduced as a means of understanding the psychological and social influences on treatment participation (see Chapter 4). These included the SRM (Leventhal et al., 1992), SCT (Bandura 1991), TA (Bordin 1979), BTP (Kazdin et al., 1997) and the COM-B system: capability, opportunity motivation – behaviour ((Jackson et al., 2014; Michie et al., 2011). Testing these theories was not an aim of this thesis, but their utility in SLT is revisited in light of the thesis findings

SRM (Leventhal et al., 1992): Evidence from the empirical studies in this thesis confirms that parents hold a pattern of beliefs about their child's SLCN and treatment, and respond emotionally. The way that they interpret and represent their child's problem is commensurate with the SRM (Horne et al., 2004; Leventhal et al., 1992). Specific causal beliefs differentiated parents in the qualitative study and predicted attendance in the main study, although the nature of the beliefs were different (self-blame in the former, early medical experiences in the latter). Other individual components of SRM may not directly influence coping strategies in

SLT. However, when participants were characterised as above/below median scores of the main predictors of attendance and adherence, differences in beliefs were present. Limitations notwithstanding, these groupings revealed different patterns of beliefs about their child's SLCN which may be of predictive value in understanding participation in SLT. Parents' personal experiences of SLT also varied within the qualitative study. This may suggest that viewing an individual's illness schemata as a whole, may be fruitful in understanding participation. Some studies have examined relationships of the whole model using cluster analysis with, for example, quality of life and mood in patients with muscle disease (Graham, Rose, Hankins, Chalder, & Weinman, 2013) and with medication adherence in patients with hypertension (Hsiao, Chang, & Chen, 2012). In their large study (N=226) Hsiao and colleagues (2012) identified three clusters of patients with different illness schemata and found that adherence varied depending on cluster membership.

The SRM and its relationship with participation has been critiqued. Meta-analytic reviews have reported varying degrees of associations between individual components of the SRM and participation, with small to medium effect sizes or no effect demonstrated (E.g. Aujla et al., 2016; Brandes & Mullan, 2014; Hagger & Orbell, 2005). It has also been proposed that treatment beliefs may be a better predictor of adherence than illness perceptions, as they focus on the response stage and how a person deals with a problem (Leventhal et al., 2008). Two reviews concluded that illness perceptions did not predict adherence (Aujla et al., 2016; Brandes & Mullan, 2014); although others have suggested that this may reflect limitations of measurement rather than of the model (Leventhal et al., 2016) and have also identified flaws in the meta-analyses used (Phillips, Leventhal, & Burns, 2016). In their recent review of the SRM, Leventhal and colleagues (2016) indicated that the current static measures of illness and treatment representations and use of cross-sectional designs may be insufficient to reflect the dynamic nature of the SRM, affecting the understanding of behaviour change. They recommend using longitudinal designs to capture dynamic changes and cause and effect relationships. Illness perceptions continue to be relevant to the understanding of treatment participation; however, future research should take account of Leventhal and colleagues (2016) recommendations to enhance the measurement and understanding of the dynamic aspects of the SRM. The use of cluster analysis in assessing the effects of illness perceptions may also be beneficial.

SCT (Bandura 1991): Parents' self-efficacy beliefs in specific domains were prominent in predicting attendance and adherence in this research. Parents' confidence in being able to

provide instrumental care for their child was an unexpected predictor of attendance but may have reflected additional burdens or stressors within a family. Parents' confidence in being able to carry out SLT recommendations was highlighted as a difference between groups in the qualitative study and emerged as a significant predictor of parental adherence along with confidence in helping their child with SLCN. The specificity of this self-efficacy belief would be predicted by the SCT, which proposes that domain specific self-efficacy beliefs will determine which coping behaviour is initiated, how much effort will be expended and how long it will be sustained (Bandura 1997). In this thesis self-efficacy predicted coping behaviour; effort and energy were not assessed, but the SCT appears to be applicable for understanding adherence in SLT. This research did not assess outcome expectations specifically, although it included treatment expectations. Treatment expectations were lower in parents who were less confident in being able to help their child's SLCN (a significant predictor of adherence) suggesting that a focus on outcome expectations would also be beneficial in future research.

TA (Bordin 1979): In the qualitative study, poor relationships with clinicians were rarely mentioned but had a significant impact; within the main study TA did not predict either attendance or adherence, although in the characterisation of parents, TA was higher in parents with greater confidence in helping their child. The measurement of TA was a limitation. Further research is required to confirm the relevance of this theory to the study of parent participation in SLT. The concept of concordance in the adherence literature however, may be relevant given its parallels with TA. Concordance refers to the shared understanding between a clinician and patient about the nature of the illness and treatment. When present it has been associated with increased patient recognition of the need for the treatment (Horne 2006). In this thesis, treatment did not always match parents' perceptions of theirs or their child's needs, and this lack of coherence between beliefs and treatment seemed to underlie both non-attendance and non-adherence. The concordance of their beliefs with SLTherapists perspectives on SLCN may therefore have been low. Differences between parent and SLTherapists perceptions have been described previously (Marshall et al., 2007). Although the relevance of TA remains unconfirmed, the relevance of how parents' beliefs about their child's SLCN and treatment accord with those of a SLTherapist do appear relevant to enhancing the professions understanding of participation. Exploring parental beliefs about SLCN and treatment at the start of an intervention is important in achieving concordance.

BTP (Kazdin et al., 1997): Parents identified barriers and burdens in both phase 1 and 3, but in the qualitative study, their presence did not differ across groups. In phase 3, the

characterisation of participants suggested that the perception of multiple barriers was a common underlying factor in parents who were less adherent. Participants who rated the importance of a recommendation lower, who were less confident in following recommendations and in helping their child, experienced a greater number of barriers. The BTP model was originally aimed at explaining non-attendance. It proposed that the cumulative effects of multiple burdens could result in an increased risk of dropping out as attending treatment may represent an additional stressor (Kazdin 1996). This was not born out in the phase 3 research, in fact barriers only featured in the characterisation of participants with lower education levels, and who had fewer barriers. The contributions of multiple burdens to participation may still be relevant but it may be more important to consider how they contribute to perceived stress and how that influences coping strategies in parents. Higher levels of parenting stress has been shown to be associated with poorer adherence (e.g. DeMore et al., 2005; Marhefka et al., 2006).

COM-B (Jackson et al., 2014): This model was not explicitly explored within the thesis; however, mapping the present research on to this model suggests that only a proportion of potential factors associated with non-adherence were considered. The present research mainly focused on the *Motivation domain* but with one element of the *physical Opportunity* domain (relationship with the SLTherapist). Dependant on the type of barriers, practical barriers to interventions could sit in either the *physical Opportunity* or the *physical Capability* domain. The variance explained by each of the models in Phase 3, although moderate, may suggest that improvements of model fit may still be achieved with additional, as yet unknown, variables and a systematic evaluation of all known factors using this model may be valuable.

Collective Limitations

The limitations for each empirical study were listed in the previous section. General limitations will be described here.

In this thesis children with known or suspected safeguarding concerns and their families were excluded; however, the risk of non-attendance in this group is potentially raised for example, in Watson and Forshaw's (2002) study, one third of children who missed appointments were known to social care. The proportion of children with such concerns, who might have otherwise have met inclusion criteria is not known, but the levels of attendance may have

been raised by the absence of this group. The rates of non-attendance are therefore potentially much higher than 25%.

The studies used inferential statistical analyses which were largely correlational. This means that the direction of causality could not be established, for example that adherence does not influence parental self-efficacy beliefs or child outcome does not influence satisfaction.

Future research and clinical implications

This exploratory study of parent participation in SLT, had many limitations, but suggests that the direction of future research should include replication, methodological improvements, considering alternative approaches to analysis, and testing for mediating and moderating factors, with systematic exploration of known factors associated with non-participation. This thesis would suggest that the developing an intervention for enhancing attendance is viable.

- Future research should consider the use of the COM-B model in the systematic evaluation of known factors associated with participation and in the development of intervention.
- A further qualitative study exploring parental beliefs about specific treatment recommendations and homework, and the experiences of implementing them with their child, may be a helpful addition to the SLT literature and enhance the quality of future adherence studies.
- Future studies may wish to incorporate parenting stress as a variable, alongside barriers to treatment participation and in addition to family functioning. Alternative measures of TA and parenting self-efficacy could be considered.
- Future studies of participation should include measurements of parental outcome expectations.
- Future studies may wish to explore the illness perception-participation relationship utilising cluster analysis and consider a longitudinal design.

11.2.3 Wider implications: SLT Profession

This thesis focused on parental factors and their influence on attendance and adherence. It was anticipated that they would be related and that they would be significantly associated

with child outcome. The failure of treatment data to predict child outcome was unexpected and has given rise to some wider questions for the profession.

The amount of SLT offered in the main study was low and remarkably similar to a RCT examining the effectiveness of SLT in a community service, which found a limited effect of treatment on child outcome (Glogowska et al., 2000). Study designs were different and the analyses in the present research were correlational, but this does raise questions about how SLT provision for young children has developed over sixteen years. A further RCT of community SLT treatment may be warranted and services may wish to consider service delivery options to increase intervention dosage. Evidence indicates that duration of eight weeks or twenty hours of SLTherapist time is associated with the best treatment outcomes in SLT research (Law et al., 1998; Law et al., 2004). However, as optimum dosage remains unclear in SLT, depending on several factors such as type of SLCN, and problem severity (Law et al., 2004) recommendations for blanket provision are not supported. Services should instead use the evidence base to inform decisions on dosage and may wish to reconsider the common practice of modifying manualised treatments such as PCI to match available resources (Law & Conti-Ramsden, 2000; Ruggero et al., 2012).

The use of standardised assessment by SLTherapists was limited in this service, although this is only one method of assessing the needs of children, with increasing interest in the use of Dynamic Assessment approaches either as complementary, or as an alternative evaluation. Dynamic assessment incorporates test-teach-test paradigms to evaluate a child's response to interaction/intervention and their learning potential (Camilleri & Law, 2007). The present SLT service advises that the 4 week generic PCI group constitutes dynamic assessment; however, when child records were examined to obtain diagnostic and descriptive information about the children, little evidence of the evaluation, formulation and results of dynamic assessment were found. A consensus on assessing children was recently reached and recommended the inclusion of known risk factors and multiple sources of information (caregivers, educational settings, static and dynamic assessment) (Bishop, Snowling, Thompson, & Greenhalgh, 2016).

Parents receiving interventions in the Phases 1 and 3 were generally satisfied with the service received; most children made clinically important improvements, but there is a possibility that these children would have made similar progress without any intervention. Satisfied and confident parents may be important for SLT services, but this would not be satisfactory if this is all that is achieved. Specialists are needed to work with children and parents who have added

problems/complexity as they are less likely to improve easily. In addition, without systematically assessing children using recommended procedures and tests and that include known methods of identifying children with persistent SLCN, services risk providing intervention unnecessarily. The process of assessment and diagnosis and the explanations that necessarily follow may provide an opportunity for enhancing parental understanding of their child's needs and prognosis thereby informing treatment choice. This may increase participation by enhancing the coherence of parents' beliefs and concordance with those of SLTherapists.

The final implication arising from this research refers to the need to increase the involvement, motivation and commitment of all SLTherapists in research. The profile of research within the NHS continues to increase. Commitment to research development is enshrined in published research strategies such as those by NHS England (<http://www.invo.org.uk/wp-content/uploads/2014/02/NHS-England-Research-Strategy-Consultation.pdf>); and incorporated into profession specific guidance (https://www.rcslt.org/members/research_centre/about_research/research_strategy). The National Institute for Health research (NIHR) has been instrumental in increasing applied health research for the benefit of patients, providing an infrastructure linking universities to the NHS, which supports, commissions and promotes research to meet the priorities identified by patients and practitioners. Developing research capacity and activity for the benefits of patients is a priority for all Allied Health Professionals' (AHP) professional bodies, who are committed to enhancing evidence based practice (EBP). In SLT, the professional body has set up a research network including research leaders, providing a strategic perspective for the body, research champions, clinical academic advisors and a professional network of regional hubs for all members (https://www.rcslt.org/members/research_centre/champions_and_networks/introduction). Together these offer opportunities for the development of capacity, transfer of knowledge and promote research activity amongst the profession. Strategically strong foundations are in place for developing research capacity, enhancing the profile of AHP research and the sharing and application of knowledge.

Applying these ideals into a particular service can be a challenge. Managers are required to balance the demands and capacity of a service within predefined budgets while putting the needs of patients first. Commissioning is becoming increasingly complex with more commissioners from outside of the NHS whose research values or priorities may be different. Services also increasingly need to look into ways of generating income given the current

funding climate. These factors may influence the priority given to research even when a service recognises its value.

At the individual level, SLTherapists vary in their skills, knowledge, motivation and self-efficacy in a research context (e.g. Appendix 11). This also has an implication for the delivery of research in a clinical setting, with varying support from therapists in both recruitment and data collection, and in understanding the specific requirements of a research protocol. Using research as part of evidence-based decision-making is the responsibility of all SLTherapists; however, active participation in research is generally voluntary and, even with management support, the demands of a SLTherapist's clinical role often remains unchanged. A balance is required between ensuring that all SLTherapists have the necessary skills to apply research knowledge to their practice and to promote active participation in research.

Through the experience of delivering the present research, a strong focus should be on supporting local services' involvement in research, including commissioners. Increasing the number of SLTherapist posts within the NHS with a clear research component and a career path in line with NIHR clinical academic pathway would greatly strengthen the SLTherapist profile and contribution towards research and EBP.

Conclusion

This thesis presents the first evidence for what motivates parents to participate in their child's SLT. It makes proposals for future research to contribute to the generation of a model of participation in SLT, including enhancements in design and methodology and providing an opportunity for the development of targeted participation interventions. This thesis also raised questions for the SLT profession about the assessment of young children, the identification of those who require specialist interventions and the issue of dosage. Finally, in support of the goals of NIHR and Royal College of SLTherapists, increasing the involvement of SLTherapists in research is actively encouraged.

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Appendices

APPENDICES: CHAPTER FIVE

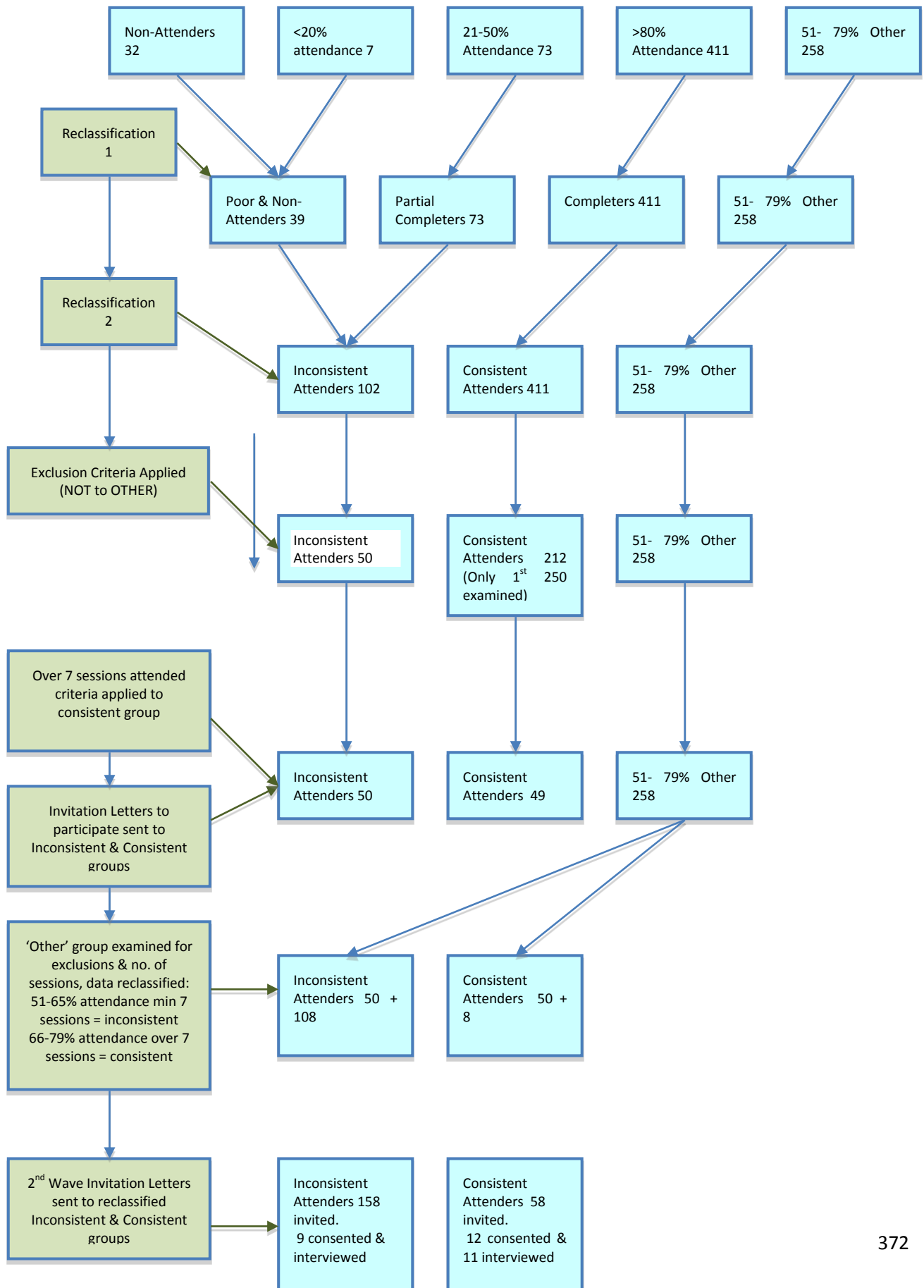
- Appendix 5.1 Recruitment Protocol
- Appendix 5.2 Consent for Contact
- Appendix 5.3 Parent Information Sheet
- Appendix 5.4 Consent Form
- Appendix 5.5 Interview Protocol

Appendix

5.1

781 cases identified by
data analyst meeting
inclusion criteria

recruitment Protocol



Appendix 5.2 Consent For Contact

Department of Psychology (at Guy's)

Health Psychology Section

5th Floor, Bermondsey Wing

Guy's Hospital

London SE1 9RT

Tel: 020 7188 0196 Fax: 020 7188 0184

To the Parents of _____

I would like to invite you to take part in a study seeking the views of parents about their experience of Speech and Language Therapy. A description of what is involved is included in the enclosed Information Sheet.

If you would like to take part in the study, could you please fill in the short form on the bottom of this page and send it back to me. Please tick the appropriate boxes and **add a telephone number** on which you can be contacted at the bottom of this page. Please return the whole page in the stamped-addressed envelope I have provided.

Yours Sincerely,

Penny Williams

PhD Student

Principal Speech and Language Therapist

Please tick the appropriate box.

YES NO

I would like to take part in this study

<input type="checkbox"/>	<input type="checkbox"/>
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If yes:

I would prefer to be interviewed at home

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

I would prefer to be interviewed at my local clinic

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

Telephone Number:

Appendix 5.3 Parent information sheet

**Department of Psychology (at Guy's)
Health Psychology Section**

5th Floor, Bermondsey Wing
Guy's Hospital
London SE1 9RT

Tel: 020 7188 0196

Fax: 020 7188 0184

PARENT INFORMATION SHEET

TITLE: Exploring parental experience of speech and language therapy in young children with Speech Language Communication needs (SLCN) to support the understanding of factors associated with parental adherence: Qualitative interviews.

Research Ethics Study Number: REC Ref 10/H0808/155
Protocol Reference: Version 1.0

Part 1 of the information sheet

You are being invited to take part in a research study. Before you decide, it is important for you to understand why this research is being done and what it will involve. Please take time to read the following information carefully and talk to others about it if you wish. You can ask me if there is anything that is not clear or if you would like more information about it. Take time to decide whether or not you would like to take part.

Background

Speech and language therapists often aim to involve parents in their child's speech and language therapy. One reason for doing this is that therapy can then happen wherever the child is and more frequently than can happen when a child is just seen in the clinic. At present we know very little about what parents think about their role speech and language therapy and what happens in speech and language therapy..

What is the purpose of the study?

The purpose of this study is to find out about your views and experiences of speech and language therapy (SLT). I hope to use the information you provide in a larger study. This larger study will consider how parents engage with speech and language therapy, what the relationship between this and the child's progress is and also how this relates to parents satisfaction with SLT services. Understanding these relationships can help us improve the way we work with children and their parents. This study is being undertaken for educational purposes, as part of my PhD in Health Psychology.

Why have I been invited?

You have been asked to participate because your child has been referred to Lambeth speech and language therapy, either currently or in the past. I will be asking about 30 parents to tell me about their experiences. Some of your children will have received speech and language therapy intervention and some will not.

Do I have to take part?

It is up to you to decide. After reading this information sheet and you are interested in taking part you will be asked to return a reply slip. I will then either telephone or write to you. I will describe the study and go through this information sheet. You are also welcome to ask any questions. If you agree I will

arrange a time to meet you to. I will then ask you to sign a consent form to show you have agreed to take part before we would start the interview. You are free to withdraw at any time, without giving a reason. This would not affect the care you or your child receives from Lambeth Community Health.

What will happen to me if I take part?

The study will involve one interview with myself, where you will be asked tell me about your experiences. The interview will last about 45 minutes. The interview can either take place at your local clinic in Lambeth or at your home.

I would like to record the interview because it is often difficult to write everything down. The recording will be deleted after I have taken the information from it. I will make you a copy of the interview tape for you to keep, if you would like this.

I would also like to look at your child's health records. This will allow me to record the description of your child's difficulties, and any speech and language therapy received. All information about you and your child will be kept strictly confidential and will not contain information about your name or address. Your speech and language therapist will not know if you have taken part in the study nor will he/she have access to your interview.

Expenses and payments

You will not receive any payment for taking part in this research. However, if you come to your local clinic to be interviewed then I will refund your travel expenses. To do this please keep any tickets for transport or receipts. If travelling by car, make a note of your mileage.

What will I have to do?

I will be asking you questions about your views and experiences of speech and language therapy. The interview will focus on your thoughts of the referral process, and, where appropriate, your views on the speech and language therapy recommendations and interventions, your relationship with the speech and language therapist; the clinic setting and the reasons that therapy ended. In addition I will also ask you about your views and beliefs on your role in developing your child's language and what you think are the main features of your child's communication difficulty (specifically language, speech or dysfluency). I will also ask you some relevant background questions about you and your family. I will ask you to tell me about your experiences, there are no right or wrong answers.

What are the possible disadvantages and risks of taking part?

The main inconvenience to you is the time spent completing the interview. There is little or no anticipated risk in this study; however, some people may be uncomfortable or reluctant to answer some questions. Please remember that you do not have to take part in this study and that you are free to stop the interview at any point or to withdraw from the study without giving a reason. I will not pass this information onto anyone and this will not affect the standard of care your child receives.

What are the possible benefits of taking part?

I cannot promise the study will help you directly but the information I get from this study will help to improve our understanding of people's experiences of speech and language therapy and this may in turn assist us to provide a better service to families.

What if there is a problem?

Any concerns or complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes Part 1. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PLEASE TURN OVER

Part 2 of the Information Sheet

What will happen if I don't want to carry on with the study?

You do not have to take part in this study and you are free to stop the interview at any point or to withdraw from the study without giving a reason. I will not pass this information onto anyone and this will not affect the standard of care you or your child receives. If you withdraw from the study I will not use your interview in my report and will delete the sound copy of the interview.

What if there is a problem?

If you have a concern about any aspect of this study, you can speak to myself, the researcher (Penny Williams) or if you prefer to my supervisor (Dr Beth Grunfeld on 020 7188 0165) who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Patient Liaison Service (PALS). Contact details: Tel: 0800 587 8078 (Monday-Friday, 9am-5pm) Fax: 020 3049 4355 Email pals@lambethpct.nhs.uk or write to: NHS Lambeth PALS, 1 Lower Marsh, SE1 7NT.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the NHS clinic will have your name and address removed so that you cannot be recognised. All data will be coded (your name and other details will be removed) and encrypted. If you are interviewed in your local clinic the encrypted audio recording of your interview will be saved directly onto an NHS computer. If the interview is in your home then the encrypted recording will be taken to the nearest clinic and again saved onto an NHS computer or taken to the psychology department at Guys hospital and stored on my University computer. All the computers are password protected. The interviews will be typed up and the paper copies stored in a locked filing cabinet in the Psychology Department at Guy's Hospital. I will be the only person who will have access to the data and it will only be used for this study.

Involvement of the General Practitioner/Family doctor (GP) and Local Speech and Language Therapist

Your GP and your child's SLT will not be informed of your decision to take part in this study unless you choose to tell them.

What will happen to the results of the research study?

The results of the study will be published in academic journals. It will not be possible to identify you in any report or publication. If you would like a summary of the results please let me know and I will forward this to you on completion of the study.

Who is organising and funding the research?

This research is not funded by an external body. It is sponsored by Kings College London.

Who has reviewed this study?

This study has been reviewed by the South East London Research Ethics Committee 3 through the Research Ethics Proportionate Review Committee.

Further information and contact details

If you have any queries please do not hesitate to contact the researcher: **Penny Williams** 020 71880196 or email penny.williams@kcl.ac.uk

Appendix 5.4 consent form

Department of Psychology (at Guy's)

Health Psychology Section

5th Floor, Bermondsey Wing

Guy's Hospital

London SE1 9RT

Tel: 020 7188 0196 Fax: 020 7188 0184

TITLE: Exploring parental experience of speech and language therapy in young children with Speech Language Communication needs (SLCN) to support the understanding of factors associated with parental adherence: Qualitative interviews.

CONSENT FROM

Name of Researcher: **Penny Williams**

Please initial box

1. I confirm that I have read and understand the information sheet dated 14.10.10 (Version 1.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without mine, my child's health care or our legal rights being affected. ☐

3. I understand that relevant sections of my child's health records held within Child Health in Lambeth Community Health may be looked at by individuals from Kings College London, from regulatory authorities or from the NHS Trust where it is relevant to my taking part in research. I give permission for these individuals to have access to my child's records. ☐

4. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Researcher	Date	Signature

Appendix 5.5 Interview protocol

Interview Protocol

Exploring parental experience of speech and language therapy in young children with Speech Language Communication needs (SLCN) to support the understanding of factors associated with parental adherence: Qualitative interviews.

Background Information (Obtained from electronic patient records):

Referrer (professional/parent):

Attended initial assessment:

Attended all intervention sessions offered in x time period

Attended 50% of intervention sessions

Did not attend any intervention sessions.

Type of intervention offered:

If discharged: discharge reason

Group allocation (based on level of attendance): A B

Demographic Information:

This information will be obtained from the parents directly and any missing data from the child's health records:

Family composition:

Parents Employment status/occupation: Mother Father

Level of education

Language spoken at home:

Ethnicity: (use Lambeth PCT forms as guide with parents if not already known)

Child's main carer(s):

Child's DOB

Child's diagnosis/problem description:

Is child in Nursery? Attending playgroup?

Introduction

Thank you for agreeing to take part in this interview. The purpose of the interview is to find out about your views and experiences of speech and language therapy. For example your views on the referral process, what the therapist told you about your child, what she/he recommended to help and why you are not currently receiving speech and language therapy. In addition it will be helpful to understand your views about your child's problem and any thoughts you might have about its impact on your child and your family. I am interested in your thoughts. There are no right or wrong answers and everything you say will be treated in the strictest confidence.

Consent

When I spoke with you on the telephone you agreed to meet with me and gave your consent to be interviewed. Can I ask you to confirm this by signing this form now?

I would like to record the interview; this is because it is too difficult to write everything down. Can you confirm that you are happy for the interview to be recorded?

TURN ON RECORDER

State reference code for participant:

The past (?)

Can you tell me how your child came to be referred to SLT?

What communication problems was your child experiencing at that time? OR How would you describe your child's communication then? **(Identity)**

Did you have any worries about your child's communication thinking about then, and in their adolescent and adult life? (If none referrers concerns) **(Consequences)**

How did you feel about your child's problems? Has that changed over time? Do you feel differently now? **(emotions)**

Assessment (omit if did not attend)

What did you expect from SLT? Did it match your expectations?

What happened when you first met the SLT?

SLT recommendations and prescribed interventions (Therapeutic Alliance TA) (if any)

What did the SLT tell you about your child and their difficulties?

What did you think about the suggestions made by the SLT in order to help your child?

Were you asked to practice therapy at home with your child? Can you describe what that was like? **(self-efficacy/adherence)**

Relationship with SLT (TA)

How did you find the speech and language therapist, for example did you feel comfortable with her, uncomfortable?

How was she with your child?

What kind of things did the therapist say and do that were helpful or not helpful?

Clinic setting

What did you think about where you went for speech and language therapy?

Nature and cause of child's problems

To what extent do you feel that you understand the nature of your child's difficulties? **(Coherence)**

What is your understanding of the causes of your child's difficulties? Do you ever change your mind about this? **(Causes)**

Reasons for ending therapy

Did anything make it easier or harder to attend and participate in SLT for your child? **(self-efficacy/adherence)**

Role in language development

There aren't any right or wrong answers but what do you think helps children develop language? (prompt for who should help?)

Present NB if discharged it's still in the past

Is there anything that you do that makes your child's communication better? Which things and how do they help? **(timeline/control)**

Is there anything that makes your child's communication worse? **(timeline/control)**

Has the way you cope with your child's communication changed over time? **(timeline/control)**

To what extent do you feel you have control over your child's difficulties? **(timeline/control)**

Do you think your child's problems with communication will continue? For how long? **(timeline)**

The future

In general and overall, do you feel things are getting better or worse for your child?

What advice would you give to someone else who has a child with communication problems?

TURN OFF RECORDER

Thank you taking part in this interview. Your participation is greatly appreciated.

Check if any travel needs to be reimbursed.

APPENDICES: CHAPTER SIX

Appendix 6.1	Local GAS Audit
Appendix 6.2	SEPTI-TS
Appendix 6.3	WAI-S
Appendix 6.4	PETS
Appendix 6.5	Demographics Form
Appendix 6.6	FLQ
Appendix 6.7	BTPS
Appendix 6.8	FOCUS

Appendix 6.1 Local GAS Audit



Children & Young People's Community Speech & Language Therapy

Clinical Audit Report:

Outcome Measures: Goal Attainment Scaling (GAS)

3rd December 2014

Author: Penny Williams, Lead Clinical Specialist Speech & Language Therapist for Autism

Background

The speech and language therapy (SLT) department is committed to delivering the best outcomes for children and young people (CYP) with speech, language, communication needs (SLCN) and those with difficulties in eating and drinking. We strive to provide high quality services that are valued by CYP, their parents and other professionals, that are equally cost effective giving due regard to commissioners of the service. Ensuring that we have robust and quality outcome measurement systems is vital in evidencing this commitment and in supporting evidence based practice.

This audit follows from the recommendations in the previous outcomes audit "Speech & language Therapy (SLT) Outcome Measure" dated: 27.3.13. Following the integration of NHS community services with Guy's and St Thomas' NHS Foundation Trust (GSTFT), the two community SLT department merged and there was a commitment to harmonise policies and procedures including the use of a single outcome measure across the team. The previous audit identified priorities for action that were agreed by the SLT leadership team. The priority actions were:

- to specify which outcome measure to be used
- to train staff in the measure
- to place outcome measures as an agenda item in line management & supervision meetings with staff.
- To undertake a yearly audit of outcome measurement

Additional recommendations related to the methodology of the audit, including improving the return rate.

These actions were all achieved.

Two outcome measures were identified that were relevant. Goal Attainment Scaling is an individualised criterion referenced measure that is similar to a behavioural objective whereby:

- Selection of goals that are observable and repeatable
- Specification of conditions under which performance is measured
- Criteria for success stated in measurable terms
- Goals to be achieved within time limits

Additionally with GAS five possible outcomes (-2 to +2) are specified. It measures qualitative change, is applicable to all areas of intervention and can be particularly beneficial in measuring low, difficult to discern, levels of achievement *Palisano (1993)*.

The second measure: Focus on the Outcomes of Communication under Six (FOCUS) (Thomas-Stonell, Robertson, Walker, Oddson, Washington & Rosenbaum 2012), relates to the measurement of change in a child's communication and interaction in real world situations, evaluating the so-called 'downstream effects of speech and language therapy intervention. As this measure is validated for use only with children under the age of six it has obvious limitations as a department wide clinical outcome tool; however, it is currently being piloted by SLTs in Early years, children centres and mainstream primary schools. This measure is not included in this current audit.

Clinical Audit design

Aims:

This audit was undertaken to evaluate the quality, consistency and application of care group standards (where known) of GAS in the SLT department and to make any relevant recommendations to ensure that the standards are maintained to the highest level.

Population

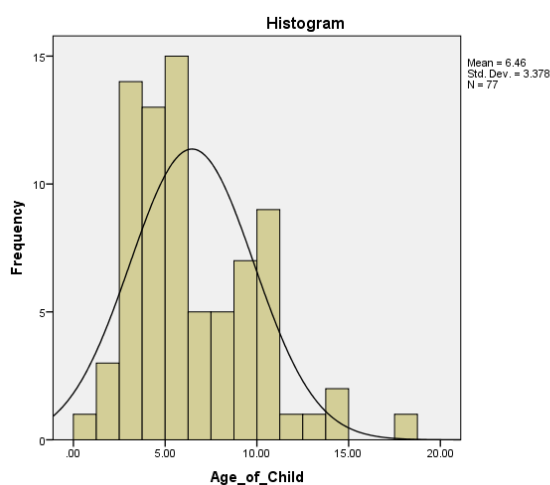
The outcome measures reported here relate to CYP in Lambeth & Southwark who were referred to SLT after 1st September 2013. This date was selected to ensure that SLTherapists would have completed their training and would coincide with the launch of the use of GAS within the department.

Sample Size:

81 case records were examined. (NB This resulted in a sample of 32 GAS outcome sheets to be evaluated representing 32 children but a proportion included more than one target).

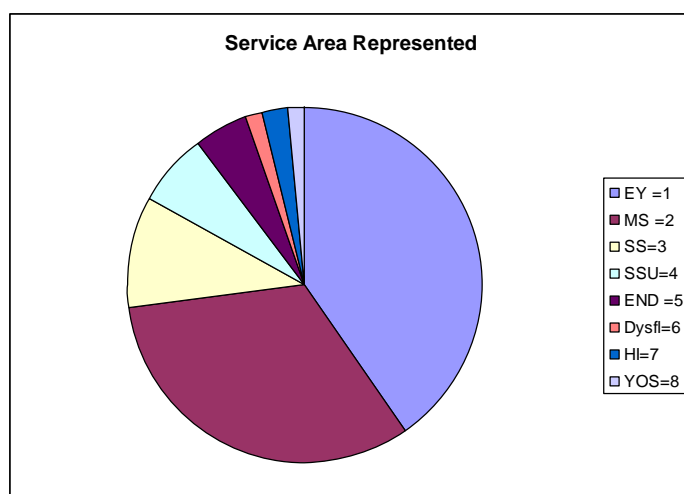
Age range:

The children ranged in age between 10 months and 18 years, mean age 6 years.



Service Area represented:

The majority of children were being seen within the Early Years & community Service, followed by those being seen within the Mainstream schools service then Special schools & Units (although separated out in the diagram below). This sample is considered broadly representative of the balance of service delivery across the SLT department.



Key: EY: Early Years; MS: Mainstream schools; SS: Special Schools; SSU: Specialist Units; END: Early Years Neuro-disability; Dysfl: Dysfluency; HI: hearing Impairment; YOS: youth offending service.

Data collection strategy

An information analyst from GSTFT provided an Excel workbook containing details of referrals to SLT teams on both Lambeth and Southwark RiOs dated on or after 01/09/2013, excluding those children whose records have been logically deleted.

A pivot table allowed selection of an SLT from a drop-down menu thus producing a randomly selected client ID for those referrals allocated to that SLT.

Details of all referrals were included in the body of the pivot table, in numerical order of ClientID, so that the referral(s) could be identified if required. HCPs may have appeared twice in the drop-down if they have allocated referrals on both Lambeth and Southwark RiOs and have their names spelt differently on those RiOs.

A list of randomly selected CYP by individual SLT was then created and the author subsequently examined RiO records for each case. At the point of examining case records there were occasions whereby the randomly selected client was not allocated to the named SLT. In these instances the caseload of the selected SLT was examined and a case randomly selected at that point. Where no GAS targets were uploaded and it was feasible given time pressures, SLTs were emailed directly to request a copy of the GAS target for that individual. The SLT sample included permanent and locum staff but not all SLTs were represented.

This strategy was considered to be cost effective and time efficient as it involved one member of staff and was not highly dependent on individual SLTherapists responding. It took approximately 7 hours to obtain the raw data. It also had the potential to reduce bias in the sample i.e. that individual may write or amend targets solely for the purpose of the audit. The sample is therefore considered potentially representative of a snapshot of current practice within the department.

Questions: (Data recorded on an excel spreadsheet)

Operational standards:

GAS: Questions related to the presence of a RiO progress note specifying targets, if GAS was uploaded and the name of the document uploaded, if not uploaded where it was saved, and whether it was outcomed and an explanation if not. In addition where no GAS targets were present a record was made as to whether any other type of target was included and an explanation of the reason for absence of the GAS target.

General: to facilitate a degree of comparison between this and the previous audit questions were also included relating to the recording of the SLTherapist name, address, circulation list, and plan of action.

Quality:

The outcomes were recorded in the spreadsheet and collated utilising a pivot table designed to collate GAS outcomes. Questions related to the type of measurement used: single versus multiple, if 5 outcomes were included for each target, if the levels were clearly defined as per GAS methodology, if the difference in the levels e.g. expected outcome, more than expected, much more than expected, was appropriate and descriptions of errors noted. The presence or absence of an overall aim, statement of the frequency of activities and timescale were also noted.

Department & Care group Standards

Department:

SLTherapists were directed to use GAS with all clients from September 1st 2013

Care Group Standards:

Known standards: source: email and Clinical Guidance documents (NB these documents had not yet been circulated to the team)

Outcomed Targets should be uploaded to RiO.

Early Years:

Following assessment and at the commencement of intervention, a Goal Attainment Scale (GAS) target will be written and discussed or potentially distributed to parents and other relevant agencies (including nurseries). "All children would have GAS targets either as a paper copy or the content of which is written in the progress notes. GAS target/s are unlikely to be developed on the first contact with a child as the service allows for an element of assessment over time/contacts."

Schools:

All children on the specialist caseload will have GAS targets. Targets will be provided for inclusion in the pupil's IEP/ provision map. Aims will be provided on standard goal attainment scaling (GAS) therapy aims form. Where school request the SLT to be involved in setting the IEP aims can be included in this format (and copied and uploaded to RiO as per usual practice).

Early Years Neurodisability

The outcome measure being used by Community Speech and language Therapy is GAS (Goal Attainment Scaling). (NB GAS targets are only currently been used for new referrals from October 1st 2014).

Hearing Impairment

Goal Attainment Scaling (GAS) will be used to set and outcome SLT targets. Gas target forms indicating the child's progress with SLT goals and outcomes of therapy will be distributed to parents and relevant professionals at the end of the intervention period. These will be uploaded to RIO.

Staff Training in Goal Attainment Scaling:

Between May-August 2013 all SLTherapists employed at that time were trained in the use of GAS using a workshop format. Each therapist attended 2 workshops led by Dr Vicky Slonims, SLTherapist and/or facilitated by Penny Williams. Therapist were required to email a completed set of GAS targets prior to the second workshop to support tailoring of the second session to assist in individuals development in writing GAS targets. Initial workshops were videoed to allow training to be cascaded to new starters.

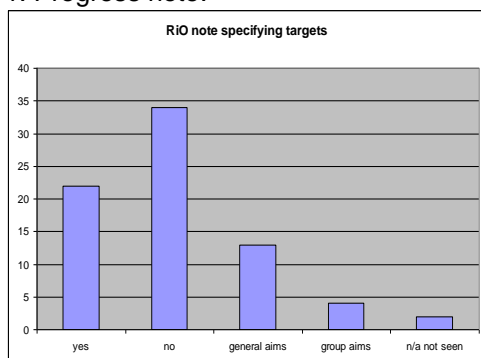
Current practice for training of new staff: new starters are trained in GAS by their line manager and directed to the video materials and resources of the original workshop. All staff are required to bring GAS targets to line management for discussion.

Results

82 records were examined in total and resulted in 32 GAS Outcome sheets available for evaluation.

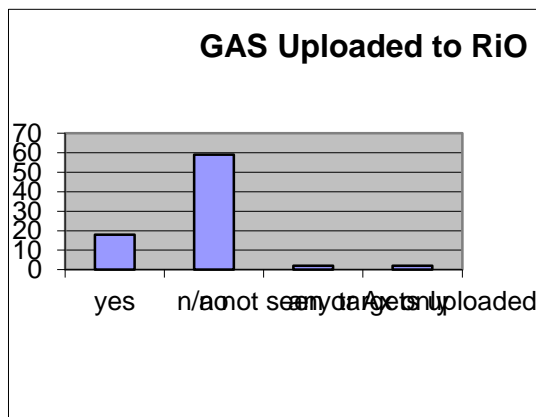
Operational standards:

1. Progress note:



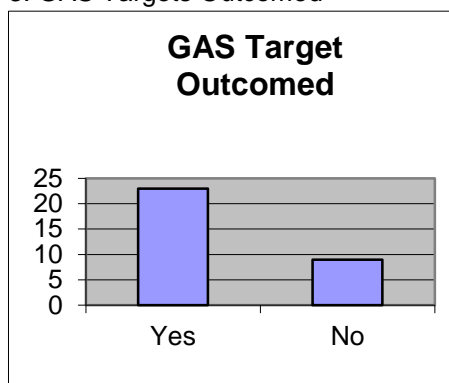
For the majority of cases (n= 34) a progress note did not specify targets or indicate that targets had been set, some did include general aims (n= 13) and some included the aims of an overall group (n=4) that a child was participating in.

2. GAS Uploaded to RiO



In the majority of cases (n=59) a GAS target was not uploaded, in two cases a target had been uploaded but it was not GAS. In Eighteen cases the GAS target had been uploaded. There were two cases where the child had not yet been seen.

3. GAS Targets Outcomed



In total thirty two GAS outcome files were available, twenty three were outcomed and nine were not. Of those that were not, explanations included that they had only just been set or were not due for review (n=6) and therefore it was appropriate that they were not uploaded. It was noted however, that for one case despite the reason given, no GAS targets had been uploaded for any of the previous blocks of intervention received by the child. The explanations for the remaining three were 'a change in level of commissioning in a school so child not prioritised', one was outcomed in response to the audit and the final case no explanation was given.

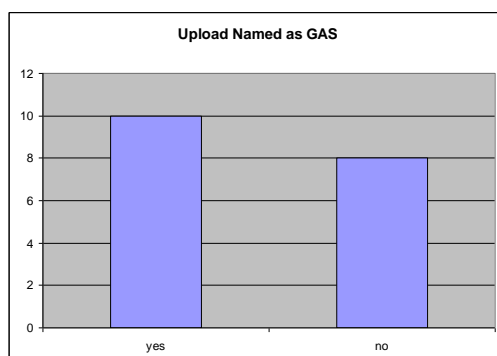
Of these thirty two 56% (n=14) of these were not uploaded. Of these fourteen cases six were not outcomed indicating that the remaining eight would have been expected to be added to RiO.

4. Explanation for absence of GAS target

Rio Progress notes were examined to identify potential reason why no GAS targets were available and where a target was requested directly from a therapist but not available, the therapist provided an explanation. In a number of cases the reason was not known. In many cases the child had not yet been seen for intervention (n=7), in others (n=6) they were discharged for any of the following reasons: intervention was not required, failure to attend appointments, moved out of area or the school did not commission a SLT service. Seven cases had received intervention and there was no obvious reason why a GAS target had not been set. Intervention included groups: (Communication Play Group, Vocabulary group) and individual intervention (Lidcombe) all were in the Early years Care Group. There were also two cases where a programme for school was recommended but there was no evidence of what this was.

Three cases were children in a special school who were not being seen for specialist intervention and two were seen for feeding but were not new referrals (see Care Group Standards).

5. Upload Naming Protocol



Ten documents (56%) included 'GAS' in the title, the remaining eight (44%) did not but included 'targets' in the document.

6. File location of GAS outcomes prior to uploading?

SLTherapists who returned GAS outcome sheets when requested, were asked to state where the document is saved prior to be placed on RiO. Five individuals stated that they were saved in the schools folder on Comshare (shared drive), two said it was saved on their 'p' drive, one on an encrypted memory stick, four did not say.

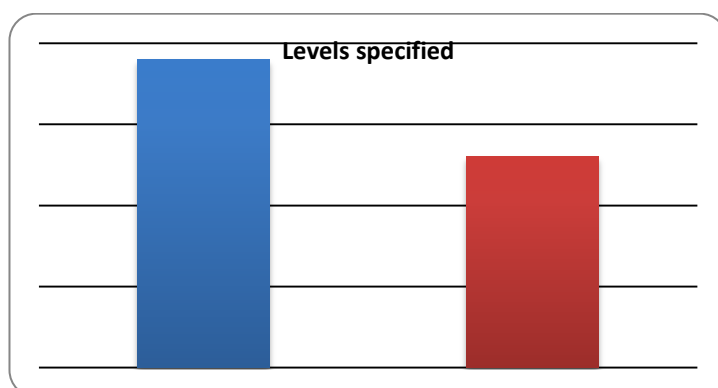
Quality: Following the pre-defined format for writing GAS targets

1. Five levels defined.

All (94%) but 2 cases defined the five levels required representing -2 less than expected, -1 current level, 0 expected outcome, +1 more than expected and +2 much more than expected.

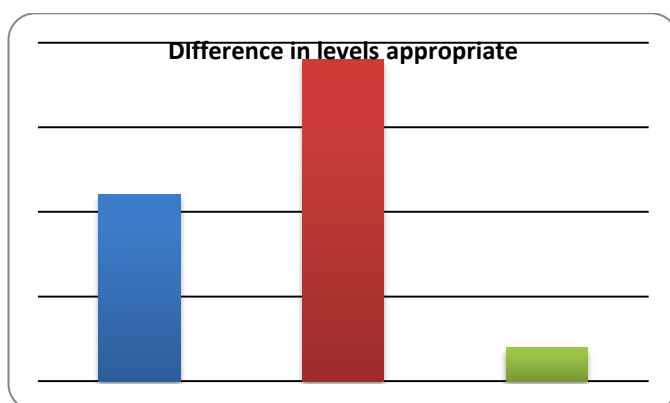
2. Levels clearly specified

This refers to the clear identification of prompts, setting and context. 41% did not meet the criteria.



Errors generally related to how difficult it was to see what was expected to be seen in the child when they achieved a certain level and how they were defined. For example use of informal and vague language "around ¼ of the time" "reduced", "engage in joint attention", play alongside 6 times in 3 minutes"; referring to but not defining a strategy "making pictures strategy". For the majority the errors related to not defining, or being inconsistent, with the definitions of adult support, context and prompts

3. Difference in levels appropriate



The difference in levels was not appropriate in 59% of the outcome sheets examined. Errors could be categorised into three types: a. specifying the loss of a skill in a child, b. Step in levels too narrow and c. Levels including multiple targets.

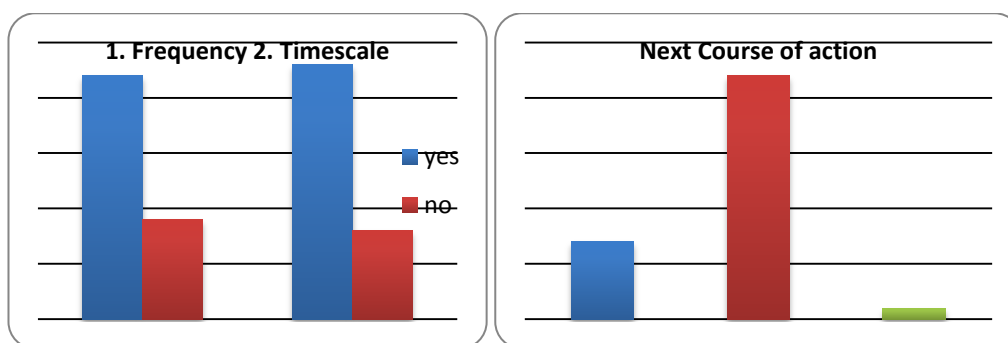
a. A number of cases (n=8) used the -2 less than expected to suggest that a child would actually lose a pre-acquired skill e.g. unable to say 'k'; this might only be anticipated in certain childhood conditions.

b. Typical levels (n=14) rose in equal increments or there was very little difference between the levels and did not take into account the time period covered by the intervention e.g. 2/4 3/4 4/4 or 5/10 7/10 10/10. It was also not possible to check if these levels were appropriate based on a child's previous response to therapy.

c. Levels specified were inconsistent, for example changing different aspects at each level 'level of prompt & word/phrase/sentence level'. Of greater significance is where the levels related to different areas when it would be highly unlikely for an intervention in one area to generalise to another. For example we wouldn't expect a child to understand in and on when focus was on big/small and where the baseline was a receptive but the expected outcomes are expressive. Others included multiple areas of intervention which would better be served by having individual targets for each, for example situation-based emotions, desire-based and then +2 being belief-based emotions and sound identification, syllable clapping and blending. There were also some examples whereby the type of prompt changed switching between two different types of prompts: eye gaze versus verbal, which would not necessarily equate to an improvement.

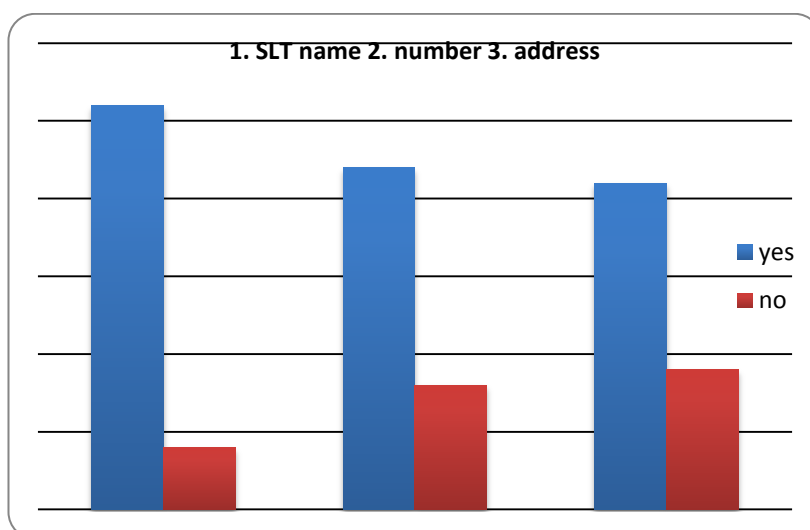
4. Client needs, overall aim, frequency and timescale, next course of action





The majority of respondents did not include an overall aim, outline the child's needs and include a plan of action but this seemed to be related to the service area or template used (see appendix) and the use of the GAS outcome sheet for multiple purpose. For example in schools this was more likely to be used as a report and hence this additional information was present, whereas in other service areas it seemed to be used as a tool for SLT use only. The majority did specify frequency of activities (72%) and timescale (69%) for review.

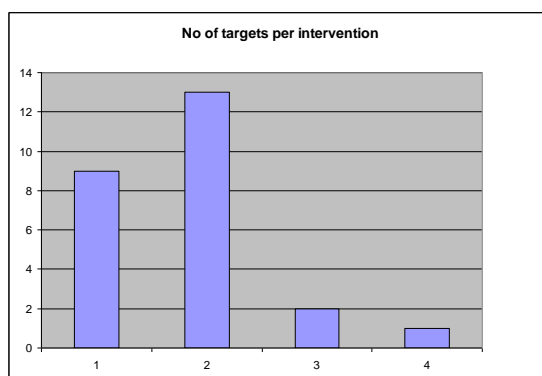
5. SLT name, number and address



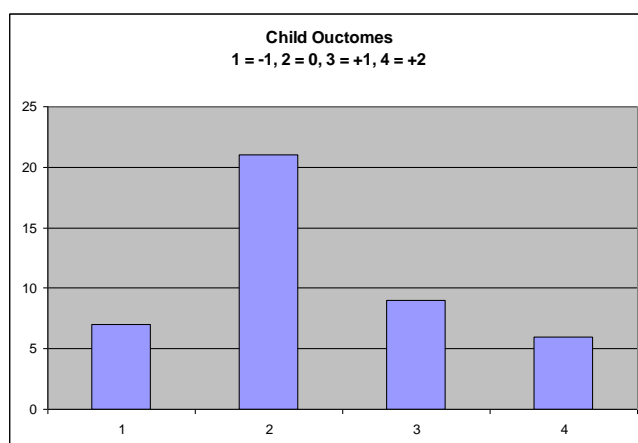
Given that a percentage of the GAS outcome sheets were not uploaded and were saved elsewhere the absence of this basic information may be explained by the use of the GAS outcome sheets informally in the first instance or in dependent on which GAS template used (see appendix).

6. GAS Outcomes

Outcomes were not categorised into specific clinical areas nor were any reasons for poor outcomes considered. The GAS targets representing twenty three children were outcomed (72%) and of those sixteen (70%) were measured as a single outcome rather than taking multiple measurements over time. It is possible that parents or education staff did not complete the measure at home leading to the use of a single measure of outcome or that SLTherapists did not evaluate outcome on a regular basis, choosing only to do it at review.



57% of the cases seen were provided with a single target for the intervention block, 39% of children were given one target per intervention, with two SLTherapists providing three recommendations and one providing four. There is currently no department-wide standard relating to the number of targets per child, although historically one target per child was recommended in schools.



The above table represents a total of 43 targets written for the 23 children. 16% achieved an outcome of -1, that is they stayed at their current level after intervention. 49% achieved 0 - the expected outcome; 21% achieved +1, more than expected and the remaining 14% achieved +2, much more than expected. Given that for a proportion of targets the difference in levels was often small it is not possible to judge if those outcomes of +1 and +2 truly represent more and much more than expected but overall 84% of children benefited from the intervention offered by SLT.

Summary

There was a general inconsistency in both the application of operational standards and the quality of the GAS targets written. It is possible that there was some confusion regarding whether the previous operational standards relating to target setting still applied, which they did. Subsequently this has been clarified and recently more specific standards relating to GAS have been defined in SLT operational guidance documents. In relation to record keeping, there was occasionally a mismatch between what is stated on RiO and what was available, for example no reference to GAS targets being set in a progress note when they had and there was no consistency in the naming of documents making locating targets more difficult. The main failure in standards was the uploading of outcome targets whereby 44% of those which would have been expected to have been uploaded where not. This may be due in part to RiO access limitations but there were clearly some cases where there was also no history of GAS targets being uploaded. There were also a number of cases where there was no identifiable explanation as to why a GAS target had not been written and a number of cases where general or group targets were referred to rather than an individual target for a child.

In addition to this audit, a research study is currently underway within the department that requires SLTherapist to return outcomed GAS targets for specific children. Of note is that, so far, outcomed GAS targets were NOT available for 32% of the cases (although a small proportion of these were cases where the child and family had not engaged in therapy). This is a specific cohort of children seen in Early Years and followed up between 6-8 months following their initial referral and who have typically only been seen for a specific 'intervention: 'Communication Playgroup'. Informal communication with SLTherapists at the time suggested that there was a period of time whereby they were under the impression that GAS targets were not to be written for the communication playgroup.

There was also significant variation in terms of quality this appeared to be related both to the methodology of writing GAS targets specifically, but also in writing an appropriate target for an individual child. This will have an impact on how easily the actual outcomes both for an individual child and at the service level can be interpreted. The GAS methodology was introduced into the department in September 2013 and since that time the department has grown significantly. As a result of staff changes, the application of the subsequent method of training and cascading the knowledge employed was insufficient.

Despite these challenges this audit demonstrated that 84% of the children who were provided with GAS targets benefited from the SLT intervention. All GAS targets reflected a behavioural change in the child or adult (whomever was the target of intervention) and both these points are an improvement on the previous outcomes audit.

Recommendations

- Operational Standards should be clearly specified for GAS and shared across the team and with locum staff.
- Standards should also include reference to use of a RiO progress note and naming protocols.
- A single GAS template should be used across the department.
- A group of GAS champions should be identified to take responsibility for training new staff, ensuring quality and to review existing bank of targets.
- Caution should be expressed when using the Bank of Targets as a random sample examined showed inconsistency in the levels of difference, accuracy of descriptions & definition of level of support required NB GAS Frameworks are addressing these. In addition SLTherapists should be aware that targets should be adapted for an individual child based on their expected response to therapy within a particular time frame.
- A master class in GAS target writing could be included in the next whole team away day focusing on quality.
- Writing targets should continue to be a regular item within line management and also clinical supervision.
- Some of these recommendations may be superseded by the planned integration of GAS target setting and RiO.
- The audit should be repeated annually.
 - The next audit should consider including an evaluation of whether the targets was appropriate for an individual child.

Penny Williams
Lead Clinical Specialist SLT for Autism

APPENDIX 1

Early Years Master

Speech & Language Therapy Target

Name:	DOB:	Date set :
--------------	-------------	-------------------

Level of expected outcome	Description Target _ of _	Monitoring of progress (including date of monitoring)							
		1 _/_/_	2 _/_/_	3 _/_/_	4 _/_/_	5 _/_/_	6 _/_/_	7 _/_/_	8 _/_/_
+ 2 Much more than expected									
+1 More than expected									
0 Most likely outcome									
-1 Current level									

Strategies for achievement of target
<ul style="list-style-type: none">

APPENDIX 2: Mainstream Schools Master

Speech & Language Therapy Target

Name:	DOB:	School:
Date set :	Review Date:	Number of Targets:
People Involved: Class teacher, LSA/TA, SENCo, parents/carers		Recommended frequency of activities:

Level expected outcome	Description Target _ of _	Monitoring of progress (including date of monitoring)							
		1 _/_/_	2 _/_/_	3 _/_/_	4 _/_/_	5 _/_/_	6 _/_/_	7 _/_/_	8 _/_/_
+ 2 Much more than expected									
+1 More than expected									
0 Most likely outcome									
-1 Current level									
-2 Less than expected									

Strategies for achievement of target
Suggested Activities: Classroom strategies Useful Resources: Summary and Recommendations:

Appendix 6.2 SEPTI-TS

THE SELF-EFFICACY FOR PARENTING TASKS INDEX—selected items from TODDLER SCALE (SEPTI-TS)

We are interested in your thoughts about various aspects involved in parenting a young child. More specifically how confident you feel you are as a parent in your ability to positively influence the behaviour and development of your child. There are no right or wrong answers and your answers are confidential. Please circle the comment that reflects your answer.

1. Even when I have had an unusually distressing day, I think my child knows I am available to meet his or her emotional needs.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

2. I believe that I adequately meet my child's needs to feel secure and accepted.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

3. When my child needs me, I am able to easily put aside whatever else I may be doing.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

4. I find it difficult to always be available to provide my child with the comfort he/she needs in dealing with the many frustrations and fears that children face each day.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

5. Providing physical comfort for my child is easy for me.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

6. I am usually willing to stop what I'm doing and cuddle my child when he/she seems to need affection.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

7. I am often too preoccupied with my own problems to keep up with my child's changing emotions.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

8. I am able to sense when my child is starting to become distressed.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

9. My child knows that I understand when his/her feelings are hurt.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

10. I think my child knows by my behaviour how much I really adore him/her.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

11. My child feels very loved by me.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

12. I think I am tolerant and understanding when my child displays negative emotions.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

13. I find it very distressing when my child isn't in a good mood.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

14. I definitely fulfill my parental duties when it comes to providing emotional support for my child.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

15. When my child has a problem, he/she knows I will want to help.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

16. Disciplining my child does not seem to be coming as naturally to me as other parts of parenting.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

17. I have trouble getting my child to listen to me.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

18. Other parents seem to have more success with setting limits for their children than I do with my child.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

19. Setting limits for my child is relatively easy for me.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

20. When my child tests the limits that I have set up, I find myself becoming extremely discouraged

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

21. Telling my child "no" when safety isn't the issue is hard for me.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

22. I allow my child enough freedom to actively explore the environment.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

23. I can always think of something to play with my child.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

24. I am a fun playmate for my child.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

25. I find it hard to loosen up and just play with my child.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

26. I am able to get actively involved in playing with my child.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

27. Playing is a part of my relationship with my child that I have very little difficulty with.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

28. I really need to learn how to just have fun with my child.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

29. I think I spend an appropriate amount of time just playing with my child.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

30. I believe my child learns a great deal from my efforts to show him/her things.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

31. Assisting my child with learning to talk and understand words is a part of parenting that I leave to others.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

32. Sitting down regularly with my child to read or do some other one-on-one activity is not difficult for me.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

33. I am probably not that great at teaching my child about the world.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

34. I have some difficulty figuring out the appropriate level of instruction when I'm trying to explain something to my child.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

35. Helping my child learn colours, names of objects, etc. is not one of my strongest points.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

36. My child learns more from me than anyone else in his/her life.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

37. I easily find opportunities to point out things about the world during my daily interactions with my child.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

38. Although I would like to help my child learn more about his/her surroundings, this is an area of parenting that I do not feel well-equipped for.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

39. I have been able to establish a daily routine with my child that feels comfortable to both of us.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

40. I am able to provide my child with a comfortable amount of daily structure.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

41. I have been successful in getting my child to eat on a fairly regular schedule.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

42. I feel like I have no control over my child's sleep habits.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

43. I am not very good at getting my child to stick to a regular daily schedule.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

44. Although I have tried to train my child to eat well, my efforts have been met with very little success.

Strongly agree	Agree	Somewhat	Somewhat	Disagree	Strongly
----------------	-------	----------	----------	----------	----------

		agree	disagree		disagree
--	--	-------	----------	--	----------

45. I don't seem to be able to establish a regular bed time routine with my child.

Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree
----------------	-------	----------------	-------------------	----------	-------------------

46. I have worked out a fairly regular morning routine with my child.

Strongly Disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly Agree
-------------------	----------	-------------------	----------------	-------	----------------

Thank you for your time and effort in completing this questionnaire.

Appendix 6.3 WAI-S

Working Alliance Inventory Short Form (C)

Instructions

On the following pages there are sentences that describe some of the different ways a person might think or feel about his or her child's speech & language therapist.

As you read the sentences mentally insert the name of your child's therapist in place of _____ in the text.

Below each statement inside there is a seven point scale:

1	2	3	4	5	6	7
Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always

If the statement describes the way you always feel (or think) circle the number 7; if it never applies to you circle the number 1. Use the numbers in between to describe the variations between these extremes.

This questionnaire is CONFIDENTIAL; neither your child's speech & language therapist nor the SLT department will see your answers.

Work fast, your first impressions are the ones we would like to see. (PLEASE DON'T FORGET TO RESPOND TO EVERY ITEM.)

Thank you for your cooperation.

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1. _____ and I agree about the things I will need to do in therapy to help improve my child's situation.

1	2	3	4	5	6	7
Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always

2. What I am doing in therapy gives me new ways of looking at my child's communication problems.

1	2	3	4	5	6	7
Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always

3. I believe _____ likes me.

1	2	3	4	5	6	7
Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always

3a. I believe _____ likes my child.

1	2	3	4	5	6	7
Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always

4. _____ does not understand what I am trying to accomplish for my child in therapy.

1	2	3	4	5	6	7
Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always

5. I am confident in _____'s ability to help me and my child.

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always
-------	--------	--------------	-----------	-------	------------	--------

6. _____ and I are working towards mutually agreed upon goals.

1	2	3	4	5	6	7
Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always

7. I feel that _____ appreciates me.

1	2	3	4	5	6	7
Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always

8. We agree on what is important for my child to work on.

1	2	3	4	5	6	7
Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always

9. _____ and I trust one another.

1	2	3	4	5	6	7
Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always

10. _____ and I have different ideas on what my child's problems are.

1	2	3	4	5	6	7
Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always

11. We have established a good understanding of the kind of changes that would be good for my child.

1	2	3	4	5	6	7
Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always

12. I believe the way we are working with my child's communication problems is correct.

1	2	3	4	5	6	7
Never	Rarely	Occasionally	Sometimes	Often	Very Often	Always

Thank you for your time and effort in completing this questionnaire.

Appendix 6.4 PETS

Parent Expectancies for Therapy Scale (PETS)

Before you start speech & language therapy with your child it would be helpful to learn your views about the treatment your child will receive. Please circle the statement that reflects your answer.

1) How much do you believe that the treatment at the clinic will help your child's communication skills?

Not at all	Very little	Somewhat	A fair amount	A great deal
------------	-------------	----------	---------------	--------------

2) How much do you believe the treatment will help you in being a parent?

Not at all	Very little	Somewhat	A fair amount	A great deal
------------	-------------	----------	---------------	--------------

3) How much time do you think you will have to spend outside the sessions on assigned tasks or activities related to treatment?

None	Very little	Some time	A fair amount of	A great deal of
------	-------------	-----------	------------------	-----------------

4) How much of a role do you believe that you will have in your child's treatment?

A very small role	A small role	A medium role	A large role	A very large role
-------------------	--------------	---------------	--------------	-------------------

5) I believe that the nursery will have to be involved in the therapy.

Not at all	Very little	Somewhat	A fair amount	A great deal
------------	-------------	----------	---------------	--------------

6) I believe that my child will improve quickly.

Do not believe	Hope	Somewhat believe	Believe for the most part	Strongly believe
----------------	------	------------------	---------------------------	------------------

7) I believe that only my child will be seen in treatment.

Strongly Believe	Believe	Somewhat believe	Doubt	Do not believe
------------------	---------	------------------	-------	----------------

8) I believe that it will take a long time for my child to improve.

Strongly Believe	Believe	Somewhat believe	Doubt	Do not believe
------------------	---------	------------------	-------	----------------

9) I believe that all the information that I give to the speech & language therapist will be confidential.

Do not believe	Doubt	Somewhat believe	Believe	Strongly believe
----------------	-------	------------------	---------	------------------

10) I believe sessions will be once a week for a certain number of weeks.

Do not believe	Doubt	Somewhat believe	Believe	Strongly believe
----------------	-------	------------------	---------	------------------

11) Once therapy begins, I believe that my child's problems will improve.

Do not believe	Doubt	Somewhat believe	Believe	Strongly believe
----------------	-------	------------------	---------	------------------

12) I believe that this treatment sounds reasonable for the problems that my child has.

Do not believe	Doubt	Somewhat believe	Believe	Strongly believe
----------------	-------	------------------	---------	------------------

13) I believe this form of treatment will help me better understand my child's communication problems.

Do not believe	Doubt	Somewhat believe	Believe	Strongly believe
----------------	-------	------------------	---------	------------------

14) I believe I will be motivated to work in this type of treatment with a therapist.

Do not believe	Doubt	Somewhat believe	Believe	Strongly believe
----------------	-------	------------------	---------	------------------

15) I believe this treatment will be valuable in treating my child's problems.

Do not believe	Doubt	Somewhat believe	Believe	Strongly believe
----------------	-------	------------------	---------	------------------

16) I believe this treatment will improve my child's communication skills at home or at school/nursery.

Do not believe	Doubt	Somewhat believe	Believe	Strongly believe
----------------	-------	------------------	---------	------------------

17) I believe that this treatment will make my child's problem worse.

Do not believe	Doubt	Somewhat believe	Believe	Strongly believe
----------------	-------	------------------	---------	------------------

18) I believe the therapy described is worthwhile.

Not worthwhile	A little worthwhile	Moderately worthwhile	worthwhile	Very worthwhile
----------------	---------------------	-----------------------	------------	-----------------

19) I believe I will have to do a lot of work outside of the sessions in order for my child to improve.

Do not believe	Doubt	Somewhat believe	Believe	Strongly believe
----------------	-------	------------------	---------	------------------

20) How would this treatment compare in effectiveness with your own attempts at dealing with the problem?

Much worse than own attempts	A bit worse than own attempts	Same as own attempts	A little better than own attempts	Much better than own attempts
------------------------------	-------------------------------	----------------------	-----------------------------------	-------------------------------

Thank you for your time and effort in completing this questionnaire.

Appendix 6.5 Demographics Form

Participant Key Information Sheet

Participant Number																																																												
Child's name:																																																												
Ethnicity: (Please circle)	<table border="1"> <tr> <th colspan="2">WHITE</th> <th colspan="2">ASIAN OR ASIAN BRITISH</th> </tr> <tr> <td>British</td> <td>A</td> <td>Indian</td> <td>H</td> </tr> <tr> <td>Irish</td> <td>B</td> <td>Pakistani</td> <td>J</td> </tr> <tr> <td>Any other white background</td> <td>C</td> <td>Bangladeshi</td> <td>K</td> </tr> <tr> <td></td> <td></td> <td>Any other Asian background</td> <td>L</td> </tr> <tr> <th colspan="2">MIXED</th> <th colspan="2">BLACK OR BLACK BRITISH</th> </tr> <tr> <td>White and Black Caribbean</td> <td>D</td> <td>Caribbean</td> <td>M</td> </tr> <tr> <td>White and Black African</td> <td>E</td> <td>African</td> <td>N</td> </tr> <tr> <td>White and Asian</td> <td>F</td> <td>Any other black background</td> <td>P</td> </tr> <tr> <td>Any other mixed background</td> <td>G</td> <td></td> <td></td> </tr> <tr> <td></td> <td></td> <th colspan="2">OTHER ETHNIC GROUPS</th> </tr> <tr> <td></td> <td></td> <td>Chinese</td> <td>R</td> </tr> <tr> <td></td> <td></td> <td>Any other ethnic group</td> <td>S</td> </tr> <tr> <td></td> <td></td> <td>Not Stated</td> <td>Z</td> </tr> </table>				WHITE		ASIAN OR ASIAN BRITISH		British	A	Indian	H	Irish	B	Pakistani	J	Any other white background	C	Bangladeshi	K			Any other Asian background	L	MIXED		BLACK OR BLACK BRITISH		White and Black Caribbean	D	Caribbean	M	White and Black African	E	African	N	White and Asian	F	Any other black background	P	Any other mixed background	G					OTHER ETHNIC GROUPS				Chinese	R			Any other ethnic group	S			Not Stated	Z
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		Chinese	R																																																									
		Any other ethnic group	S																																																									
		Not Stated	Z																																																									
Mother's name: (who the child lives with, not necessarily biological)																																																												
Ethnicity: (Choose from above)																																																												
Marital Status:																																																												
Languages Spoken:																																																												
Father's name: (who the child lives with, not necessarily biological)																																																												
Ethnicity: (Choose from above)																																																												
Marital Status:																																																												

Household Composition

1. How many people live in your house? Can you tell me who each one is? (Use codes from below

Name	Age	Relationship to child	Code

- 1= Mother
- 2= Father
- 3= Adoptive mother
- 4= Adoptive father
- 5= Step-mother
- 6= Step-father
- 7= Mother's partner
- 8= Father's partner
- 9= Sister
- 10= Brother
- 11= Step-sister
- 12= Step-brother
- 13= Half-sister
- 14= Half-brother
- 15= Grandmother
- 16= Grandfather
- If other please specify

Does one of the child's biological parents live at a different address as the child? If yes, state Mother/Father

2. How many brothers or sisters does your child have? How old are they? Are they biological siblings?

OBTAIN EDUCATIONAL AND WORK HISTORY FOR PARENTS RESIDING WITH PARTICIPANT

Parent 1 (Respondent)

1. What about your own education, where did you go to school? What kind of school was that?

2. How old were you when you left school?

3. Did you take any examinations?

--	--

Final educational qualification

- 0 = none
- 1 = 1-4 GCSE passes at GSE, GCSE, O level
- 2 = ≥ 5 passes at GSE, GCSE, O level
- 3 = A levels or equivalent
- 4 = University
- 5 = Postgraduate degree
- 8 = N/A
- 9 = D/K

4. Did you do any further training or education after leaving school?

--	--

Work/professional training

- 0 = none
- 1 = on job training certificate (< 1mos)
- 2 = City & Guilds or equiv.
- 3 = Professional
- 4 = Apprenticeship
- 5 = Semi-professional
- 8 = N/A
- 9 = D/K

5. Are you working? Yes No Past

--	--

Job title _____

- 0= professionals: e.g. doctors, lawyers, teachers, managers
- 1= non-manual skilled: e.g. typist, police officer, fireman
- 2= manual skilled: e.g. toolmaker, foreman, ambulance man
- 3= partly skilled: e.g. bus conductor, postman
- 4= unskilled: cleaners, porters, messengers
- 5= chronically unemployed for the majority of adult life
- 6= homemaker who has not worked for majority of adult life
- 7= sheltered employment
- 8= still in full time education
- 9= not known

Parent 2

6. What about his/her other parent? Where did they go to school? What kind of school was that?

7. How old were they when they left school?

8. Did they take any examinations?

--	--

Final educational qualification

- 0 = none

- 1 = 1-4 GCSE passes at GSE, GCSE, O level
 2 = ≥ 5 passes at GSE, GCSE, O level
 3 = A levels or equivalent
 4 = University
 5 = Postgraduate degree
 8 = N/A
 9 = D/K

9. Did they do any further training or education after leaving school?

--	--

Work/professional training

- 0 = none
 1 = on job training certificate (< 1mos)
 2 = City & Guilds or equiv.
 3 = Professional
 4 = Apprenticeship
 5 = Semi-professional
 8 = N/A
 9 = D/K

10. Are they working? Yes No Past

--	--

Job title _____

- 0= professionals: e.g. doctors, lawyers, teachers, managers
 1= non-manual skilled: e.g. typist, police officer, fireman
 2= manual skilled: e.g. toolmaker, foreman, ambulance man
 3= partly skilled: e.g. bus conductor, postman
 4= unskilled: cleaners, porters, messengers
 5= chronically unemployed for the majority of adult life
 6= homemaker who has not worked for majority of adult life
 7= sheltered employment
 8= still in full time education
 9= not known

Appendix 6.6 FLQ

FAMILY LIFE QUESTIONNAIRE

Questionnaire filled in by:	
Relationship to child:	
Date filled in:	

Instructions for Completion

Please read each statement carefully and tick the box which you think best fits your feelings about you, your child with *Speech, Language, Communication Needs (SLCN)* and your family life.

Please tick "N/A" if the statement does not apply to you.

There is a section at the end for you to add any other comments which you think may be relevant regarding your family life.

Please try to answer all the questions.

FLQ: EXPERIENCE OF BEING A PARENT OF A CHILD WITH *Speech, Language, Communication Needs (SLCN)*

		Always	Often	Sometimes	Rarely	Never
No	Question	1	2	3	4	5
1	I lack confidence in knowing how to help my child					
2	I feel listened to by professionals					
3	Working with therapists or professionals helps me feel confident					
4	I am confident that I understand my child's level of development					
5	I feel I know how to help my child progress					
6	I feel I'm getting it wrong					
7	I have realistic milestones for my child's development					
8	I doubt my ability to help my child's development					
9	I feel frustrated at not knowing how to help my child					
10	I have coping mechanisms to help my child					
11	Professionals don't understand my family's needs					
12	It's a continual battle to get the right help for my child					
13	My child is getting the right help					

FLQ: FAMILY LIFE

		Always	Often	Sometimes	Rarely	Never
No	Question	1	2	3	4	5
14	Family life is a battle					
15	I feel guilty about not giving other members of the family enough attention					
16	My child is flexible in adapting to the demands of family life					
17	Family life is calm					
18	I know how to cope with my child when going on an outing in a public place e.g. café or restaurant					
19	I feel confident to go out to family events with my child					
20	I feel confident in making routines at home more manageable for my child					
21	I feel comfortable about having visitors to our home					
22	My child has fussy eating that makes it difficult to go away for a break					

FLQ: CHILD DEVELOPMENT

		Always	Often	Sometimes	Rarely	Never
No	Question	1	2	3	4	5
23	My child can concentrate on an activity for a short time					
24	My child can spontaneously begin communication with me					
25	My child spontaneously begins communication with other members of the family					
26	My child can request his/ her needs appropriately					
27	My child gets frustrated at not being understood					
28	My child can let me know when he/ she is hurt					
29	I know when my child feels poorly					
30	My child has repetitive behaviour and sensory interests that make it difficult to go on an outing					

FLQ: CHILD UNDERSTANDING

		Always	Often	Sometimes	Rarely	Never
No	Question	1	2	3	4	5
31	My child is good at sharing with others					
32	My child has to have his/ her own way					
33	My child is aware of other people's needs					

FLQ: CHILD SOCIAL RELATIONSHIPS

		Always	Often	Sometimes	Rarely	Never
No	Question	1	2	3	4	5
46	My child gets invited to birthday parties					
47	My child plays with other children					

48	I have to go with my child to supervise play with other children					
----	--	--	--	--	--	--

FLQ: CHILD FEELINGS

		Always	Often	Sometimes	Rarely	Never
No	Question	1	2	3	4	5
34	My child is happy					
35	My child is anxious					
36	My child is tolerant of mistakes					
37	My child is calm					
38	My child is angry					
39	My child is unpredictable					
40	My child can let me know what he/ she is upset about					

FLQ: CHILD BEHAVIOUR

		Always	Often	Sometimes	Rarely	Never
No	Question	1	2	3	4	5
41	My child understands appropriate behaviour in familiar social situations					
42	My child knows the difference between family members and strangers					
43	My child acts differently with family members compared with strangers					
44	My child is embarrassing when going out					
45	My child has repetitive behaviours make day to day life impossible					

ANY OTHER COMMENTS:

Thank you for your time and effort in completing this questionnaire.

Appendix 6.7 BTPS

Date: _____

BARRIERS TO TREATMENT PARTICIPATION SCALE (BTPS)(PARENT)

DIRECTIONS

Coming to treatment is often difficult because of the many demands on parents and families such as nursery, school, work, and other activities. It is important to understand different factors and how they affected your participation and attendance in treatment. Please answer the items below which will be used to help us make our treatment better. As you answer the questions, please think about your own situation only and things that you felt about coming to treatment. (All answers are completely confidential.)

Below are common problems that come up in treatment. For each one, place a cross in the box for the answer that applies to you.

Never a Problem	Once in a while	Sometimes a problem	Often a problem	Very often a Problem
1	2	3	4	5

Please turn the page and mark your answers.

		Never a Problem	Once in a while	Sometimes a problem	Often a problem	Very often a Problem
		1	2	3	4	5
1	My child refused to come to the sessions.					
2	Transportation (getting a ride, driving, taking a bus) to the clinic for a session.					
3	My child was in other activities (nursery, play group, drop in sessions) that made it hard to come to a session.					
4	Scheduling of appointment times for treatment					
5	Treatment lasted too long (too many weeks).					
6	Treatment was in conflict with another of my activities (classes, job, friends).					
7	Treatment did not seem necessary.					
8	I did not like my child's therapist.					
9	My child did not like their therapist					
10	Treatment was not what I expected.					
11	Information in the session seemed confusing.					
12	My child had trouble understanding treatment.					
13	During the course of treatment I experienced a lot of stress in my life.					
14	I lost interest in coming to sessions.					
15	I was sick on the day when treatment was scheduled.					
16	My child was sick on the day when treatment was scheduled.					
17	Crises at home made it hard for me to get to a session.					
18	I felt I had to give too much personal information to the therapist.					
19	Treatment added another stressor to my life.					
20	I felt treatment did not seem as important as the sessions continued.					
21	I felt this treatment was more work than expected.					
22	The atmosphere in the clinic makes it uncomfortable for appointments.					

		Never a Problem	Once in a while	Sometimes a problem	Often a problem	Very often a Problem
		1	2	3	4	5
23	I did not feel that I had enough to say about what goes on in treatment.					
24	I felt treatment did not take into account my life and problems.					
25	The therapist did not seem confident that treatment would work for my child.					
26	The therapist did not seem confident in my ability to carry out programs.					
27	My child now has new or different problems.					
28	My child's communication skills seem to have improved, therefore, treatment no longer seems necessary.					
29	Treatment did not seem to be working.					
30	There was bad weather and this made coming to treatment a problem.					
31	I do not feel the therapist supported me or my efforts.					
32	The assigned work for me to do as part of treatment was much too difficult.					
33	I did not have time for the assigned work.					
34	There was always someone sick in my home.					
35	Getting someone to look after my other child/ren so I could come to sessions.					
36	Finding a place to park at the clinic.					
37	I had a disagreement with my partner about whether we should come to treatment at all.					
38	I was too tired to come to a session.					
39	My job got in the way of coming to a session.					
40	Treatment took time away from spending time with my children.					
41	I had trouble with other children at home which made it hard to come to treatment.					

Appendix 6.8 FOCUS

The FOCUS®: Parent Form

**Focus on the
Outcomes of
Communication
Under
Six**



Thomas-Stonell, N., Oddson, B., Robertson, B.,
Walker, J. & Rosenbaum, P. © 2012

Name of Child _____

Date Completed Year _____ Month _____ Day _____

Date of Birth Year _____ Month _____ Day _____

Chronological Age Year _____ Month _____

Name of Person Completing Form _____

FOCUS Completion # _____

Name of Speech-Language Pathologist _____

FOCUS®
TOTAL
SCORE

Administration Instructions

The FOCUS® is an outcome measure that takes a 'snapshot' of your child's skills as they are today. Some items may not apply to your child right now. If so, please select "Not at all like my child". If the item is shaded, please check "Exactly like my child". Your child may begin to learn some of these skills during therapy and choosing this option will let us measure all of the changes that your child is making. Please be sure to answer every question. Thank-you.

Definitions:

"Talking", "tell", "speaks", "speech" and "words" refer to verbal speech. (e.g. "My child talks a lot.")

"Communicating", "conversations", "participates" and "asking" can be any form of communication (pecs, AAC, sign).
(e.g. "My child will ask for help.")

Part 1		Not at all like my child	A little bit like my child	Some-what like my child	A fair bit like my child	Quite a bit like my child	Very much like my child	Exactly like my child
1.	My child makes friends easily.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2.	My child is included in play activities by other children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.	My child is comfortable when communicating.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4.	My child is confident communicating with adults who know my child well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5.	My child takes turns.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6.	My child talks while playing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.	My child is willing to talk to others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8.	My child is confident communicating with adults who do not know my child well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9.	My child can communicate independently.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.	My child talks a lot.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11.	My child can string words together.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12.	My child gets along with other children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13.	My child can communicate independently with other children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.	My child's speech is clear.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15.	My child is understood the first time when s/he is talking with other children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16.	My child speaks slowly when not understood.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17.	My child speaks in complete sentences.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Scores

Part 2		Can not do at all	Can do with a great deal of help	Can do with a lot of help	Can do with a bit of help	Sometimes does without help	Often does without help	Can always do without help
1.	My child plays well with other children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2.	My child will sit and listen to stories.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.	My child can communicate effectively with adults who know my child well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4.	My child is included in games by other children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5.	My child will try to carry on a conversation with adults who do not know my child well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6.	My child will ask for things from adults s/he knows well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.	My child participates in group activities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8.	My child can tell stories that make sense.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9.	My child can respond to questions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.	My child will ask for things from other children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11.	My child can carry on a conversation with other children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12.	My child can communicate effectively with other children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13.	My child can communicate effectively with adults who do not know my child well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.	My child can be understood by other children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15.	My child can talk about what s/he is doing with adults who do not know my child well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16.	My child joins in conversations with her/his peers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scores								

APPENDICES: CHAPTER SEVEN

- Appendix 7.1 IPQR-SLCN Development: Symptoms
- Appendix 7.2 IPQR-SLCN Development: Causal Attributions
- Appendix 7.3 SLTherapist Information Sheet
- Appendix 7.4 Letter of introduction
- Appendix 7.5 Participant Information Sheet
- Appendix 7.6 Consent Form
- Appendix 7.7 Brief guidance for participants
- Appendix 7.8 Reminder Poster for Speech and Language therapists
- Appendix 7.9 Record of recommendations
- Appendix 7.10 Parent Feedback form
- Appendix 7.11 HRS II
- Appendix 7.12 M-ATIF
- Appendix 7.13 CSQ-8
- Appendix 7.14 CSPQ
- Appendix 7.15 SE-SLTR
- Appendix 7.16 IPQR-SLCN
- Appendix 7.17 SLTherapists Recruitment Feedback

Appendix 7.1 IPQR-SLCN Development: Symptoms

Development of IPQR-SLCN: Identity Scale: parent reported Symptoms

Expressive

cries, doesn't talk voice lost after surgery came back, didn't speak quickly, problems in answering questions, doesn't talk, difficulties expressing himself, saying less words talking affected, talking in single words, baby talk, few words, not speaking much, few words and babble, would occasionally join words, not talking much, few words, less than expected for age, learnt a word then stopped using it, slow to talk, can't explain things, reduced vocabulary, delayed speech, just can't talk.

Crying

Doesn't talk/not speaking much

Problems in answering questions

Can't explain things

Reduced vocabulary/few words

Gesture:

non-verbal communication delayed, would point (2), pulls her hand and shows her, points,

doesn't point

pulls my hand and shows me

Receptive

doesn't understand (2), understand home language more, can't understand, problem with understanding, can understand, didn't understand, understands

doesn't understand

Speech

not clear, lispy, nasal, not speaking clearly, not understood, can't be understood, words not clear, garbled speech, some sounds now mastered, intelligible to mother with context, can't make himself understood, not good at initial sounds, sounds not clear

doesn't speak clearly

can't be understood

Behaviour

attention problems, stubborn, can't sit down, behaving strangely, withdrawn, very intimidating, cut off, in his own world, unusual interests, happy, secure, slightly withdrawn, some unusual behaviours, physically agile, needs a confidence boost

attention problems

lack of confidence

withdrawn

in his/her own world

behaves strangely

stubborn

Fluency

stammering

stammers

Social

over friendly didn't want to talk to other children, no confidence with people, not mixing/sharing toys with peers, good eye contact, played with objects not children, shy reduced eye contact, no interest in natural things like joining others, problems with eye contact, reduced peer interaction

over friendly

shy

problems with eye contact

doesn't mix/share toys with other children

Learning

learning affected, behind with everything, delays early on, delayed milestones including motor

behind in his learning

General

maybe not normal, age appropriate on most things

Appendix 7.2 IPQR-SLCN Development: Causal Attributions

Development of IPQR-SLCN: Causal Attributions

Summary of parent statements:

Genetic/Hereditary

- Mothers side: decided it is from her side of the family, maybe mum has the same, chromosomal imbalance passed from mother to son,
- Father's side: thinks it from her partners side of the family not hers. because his father has it inheritance figures tell her he is high risk, Comes from father's side because he had similar problems when he was young. Not her side she is a fast talker. Inherited characteristics from father to a certain extent.
- No-one's: no family history, Both her and her other son are fine.
- Not specified: investigated family history, family history of similar, although they were also bilingual. hereditary? maybe genetic,

Related/potential IPQ-R statement(s)

Hereditary: it runs in mine or my partners side of the family

Summary of parent statements:

Child:

- Personality: shyness, because he wants to be, daughter chose not to talk to others, Not about anything they were doing at home more to do with her son.
- Experience: lack of experience with other children, Wondered if she had lacked constant interaction with different people (family & nursery) combined with her character/personality. his age.
- Experience: told that is might be due to just being at home with mother,
- Bereavement: Death of his mother significant but not the only thing, specialist say no-one able to say for sure. grief,
- Physiological: considered but dismissed dummy use,
- Other: it's their nature, born with it, Demands of starting education at 3.5?

Related/potential IPQ-R causal statement(s)

My child's personality

My child's age

My child's lack of experience

My child's emotional state

My child used a dummy/pacifier

My child was born with it

My child started school too early

Summary of parent statements:

Environment:

- Mother's role: mothers slow talking, Questions her role in the delay because she couldn't spend as much time with her because of her older disabled daughter. That his Mother was too sick to play and interact with him maybe related. lack of attention and stimulation due to ill mother, Not the environment because he is not alone and has siblings to talk to. Wondered if it was because she had been distracted by moving house & having a baby when she was young. she and her son have always talked to him,
- EAL: SLT said EAL might contribute, wonders about if speaking two languages is connected and if it confuses her daughter.
- Pregnancy: being very sad when she was pregnant, not eating healthy when pregnant,
- Psychological: confusion, moving house, moving between two different households. psychological component of marital break-up, an unhappy home.
- Other: born of older parents,

Related/potential IPQ-R causal statement(s)

My own behaviour - I didn't do enough

My own behaviour - I didn't do the right things when I was pregnant

My emotional state e.g. feeling down, lonely, anxious, empty.

Family problems – moving house, moving between two households, marital break-up, unhappy home.

We speak more than one language at home/a different language at home.

Summary of parent statements:

Medical/Physiological

- Peri-natal: mother thinks that other twin laid on her and took everything when she was in the womb.
- Prematurity: born prematurely because of weak placenta, born prematurely,
- Medical Procedure: surgery caused loss of voice which returned, tube in his throat long hospital stay,
- Neurological: to do with the brain and nerves, "nervosity",
- Physiological: Not hearing words properly or saying it incorrectly? problem with her body, no cause found by doctors, physiological? is it his tongue?
- Other diagnosis: diagnosed with global mental delay which explains everything, unspecified developmental delays predating mothers death, major medical conditions ruled out,
- Genetic: subtle genetic defects,
- Medicines/Vaccinations: not MMR. it's not the MMR.

Related/potential IPQ-R causal statement(s)

There were problems during pregnancy.

My child was born prematurely

My child was in hospital for a long time

The tube my child had in his throat

My child's surgery

My child's brain and nerves

My child can't hear properly

My child's tongue doesn't move properly

Genetic 'defects'

My child's other diagnosis – developmental delay

Vaccinations e.g. MMR

Other

Religion was not identified by parents as a potential causal factor in this study; however, personal experience of working with parents suggest it may be relevant.

Related/potential IPQ-R causal statement(s)

It's God's will.

Additional IPQ-R causal statements

Although parents did not refer specifically to the following items, expert consensus indicated that their retaining these original items would be appropriate in the piloting of this measure.

Stress or worry

A germ or virus

Diet or eating habits

Chance or bad luck

Pollution in the environment

Accident or injury

Appendix 7.3 SLTherapist information sheet

**Department of Psychology (at Guy's)
Health Psychology Section**

5th Floor, Bermondsey Wing

Guy's Hospital

London SE1 9RT

Tel: 020 7188 0196

Fax: 020 7188 0184

SPEECH & LANGUAGE THERAPIST INFORMATION SHEET (18.1.11)

TITLE: A pilot study to identify appropriate measures of adherence, satisfaction and self-efficacy for use with parents of young children receiving speech & language therapy (SLT) intervention.

Research Ethics Study Number: REC Ref 11/LO/0031

Protocol Reference: Version 1.0

Thank you for agreeing to support this research study. The following information should assist your understanding of what the research study is about and your role in the study. If you have any more questions I am very happy to discuss them with you.

Background

Speech & language therapists such as yourself often aim to involve parents in their child's speech & language therapy and will make a variety of recommendations for example to help practice therapy at home. One reason for doing this is that therapy can then happen wherever the child is and more frequently than can happen when a child is just seen in the clinic. At present we know very little about how parents respond to these recommendations.

What is the purpose of the study?

The purpose of this study is to find out if certain questionnaires are suitable for use by parents whose child is receiving speech & language therapy. These questionnaires look at what parents do when they are given a recommendation and why (adherence) and how confident they are in carrying out the recommendation (self-efficacy). In addition I would like to check the suitability of some questionnaires that look at how satisfied parents are with the speech & language therapy service in general. I am also interested in seeking parental views on the questionnaires and their comments on their experience of completing them. I hope to use this information in a larger study. This larger study will consider how parents engage with speech & language therapy, what the relationship between this and the child's progress is and also how this relates to parents satisfaction with SLT services. Understanding these relationships can help us improve the way we work with children and their parents. This study is being undertaken for educational purposes, as part of my PhD in Health Psychology.

Why have I been asked?

As a speech & language therapist, you are currently working with children and their parents referred to Lambeth speech & language therapy and currently receiving intervention from a speech & language therapist (either yourself or a colleague). I will be asking you to pass on information about the study to about 90 parents in order that approximately 50 will complete the questionnaires and telephone interview and make comments on them.

What will I have to do?

At the start of the study I will ask you to pass on an information pack relating to the research to all the parents whose child is currently receiving any kind of therapy. The exceptions are those children:

- Who have a chronic or current medical illness

- Who are subject to a child protection enquiry or are a 'Looked After' child.
- Who has been referred for additional intervention with myself.

In addition a parent who requires the use of interpreting services should also not be invited as I do not have funding for the use of interpreting services.

The information pack will contain a covering letter to parents, a parent information sheet, consent form and copies of four short questionnaires for the parents to complete. The questionnaires should take about 30 minutes for parents to complete and they will be asked to return them to me by post. Once I have received these I will contact you to request a copy of the recommendations you made for this parent and their child. I have enclosed a 'recommendation sheet' for you to use for this purpose. These sheets can be emailed to me or sent via internal mail. To maintain confidentiality the prescription sheet will have a code rather than the name of the parent or child. When I have received these I will then arrange to complete the final questionnaire with the parent over the phone. The telephone interview will also last about 30 minutes.

I will also be asking parents for their consent to look at their child's health records. This will allow me to record the description of their child's difficulties, and any speech & language therapy received. All information about parents and their child will be kept strictly confidential and will not contain information about their name or address.

What will the parents have to do?

They will have to complete 4 short questionnaires and return them by post to me. This will be followed by a further questionnaire that will be completed over the telephone. The questionnaires the parents will complete on their own will ask a range of questions. For example asking about the recommendations made by yourself, the speech and language therapist; asking the parents about their confidence in completing them and also about their satisfaction with speech & language therapy services in general. The parent's views on completing the questionnaires will also be asked. This should take them about 30 minutes. During the telephone interview I will be asking parents further questions about the recommendations made by yourself. This interview will also last about 30 minutes. I will also ask the parents some relevant background questions about them and their family. Parents will be advised that for all the questions there are no right or wrong answers and that I am interested in their personal views and experiences.

What will happen if parents don't want to carry on with the study?

Parents do not have to take part in this study and are free to stop the telephone interview at any point or to withdraw from the study without giving a reason. They will be told that I will not pass this information onto anyone and that this will not affect the standard of care they or their child receives. If a parent withdraws from the study I will not use their questionnaires or interview in my report and will delete the sound copy of the interview.

What if there is a problem?

If you have a concern about any aspect of this study, you can speak to myself, the researcher (Penny Williams) or if you prefer to my supervisor (Dr Beth Grunfeld on 020 7188 0165) who will do their best to answer your questions.

Will the information given by myself and the parents be kept confidential?

All information that is collected during the course of the research will be kept strictly confidential. The parents name and address will NOT be recorded on the questionnaires so they cannot be recognised from them. For this reason I will ask parents to return the consent form and questionnaires in separate envelopes. The digital recordings of the telephone interview will be encrypted and saved directly onto an NHS computer or on my University computer. All the computers are password protected. The interviews will be typed up and the paper copies stored in a locked filing cabinet in the Psychology Department at Guy's Hospital. I will be the only person who will have access to the data and it will only be used for this study.

Will I get to see the answers to the questionnaires for the parents I am working with?

You will know which parents are involved because I will ask you for a copy of the recommendations you made for them but you will not have access to any of the detailed responses to the questionnaires or have access to the parent telephone interview.

What will happen to the results of the research study?

The results of the study will be published in academic journals. It will not be possible to identify parents in any report or publication. If you would like a summary of the results please let me know and I will forward this to you on completion of the study.

Who is organising and funding the research?

This research is not funded by an external body. It is sponsored by Kings College London.

Further information and contact details

If you have any queries please do not hesitate to contact me: **Penny Williams** 020 71880196 or email penny.williams@kcl.ac.uk or penny.williams@lambethpct.nhs.uk

Appendix 7.4 letter of introduction

**Department of Psychology (at Guy's)
Health Psychology Section**

5th Floor, Bermondsey Wing
Guy's Hospital
London SE1 9RT

Tel: 020 7188 0196 Fax: 020 7188 0184

Dear _____,

I am inviting you to help me by taking part in a study deciding if questionnaires looking at the following areas are appropriate for use with parents whose child is receiving speech & language therapy. The questionnaires ask about parents' experience of the recommendations made by a speech and language therapist; parents' levels of confidence in carrying out these recommendations, beliefs about your child's speech, language communication problem and also about parents' satisfaction with speech & language therapy services in general. A description of what is involved is included in the enclosed Information Sheet.

You have been invited by your speech & language therapist because your child is currently receiving therapy. I have enclosed an information sheet about the study, a copy of the questionnaires along with a consent form and two prepaid reply envelopes. If you are willing to complete the questionnaires and interview please return the consent form in one envelope and the questionnaires in the other so that your name and address is kept separate from your answers. If you are willing to participate I would like to say thank you.

Thank you for taking the time to read this and the enclosed information and please telephone me if you have any questions.

Yours Sincerely,

Penny Williams

PhD Student

Principal Speech & Language Therapist

Appendix 7.5 Participant Information Sheet

Department of Psychology (at Guy's)
Health Psychology Section
5th Floor, Bermondsey Wing
Guy's Hospital
London SE1 9RT
Tel: 020 7188 0196 Fax: 020 7188 0184

PARTICIPANT INFORMATION SHEET (11.4.12)

TITLE: A pilot study to identify appropriate measures of adherence, satisfaction and self-efficacy for use with parents of young children receiving speech & language therapy (SLT) intervention.

Research Ethics Study Number: REC Ref 11/LO/0031

Protocol Reference: Version 3.0

Part 1 of the information sheet

I am inviting you to take part in a study to decide if questionnaires involving speech and language therapy are appropriate for use with parents. Before you decide, it is important for you to understand why this research is being done and what it will involve. Please take time to read the following information carefully and talk to others about it if you wish. You can ask me if there is anything that is not clear or if you would like more information about it. Take time to decide whether or not you would like to take part.

Background

Speech & language therapists often aim to involve parents in their child's speech & language therapy and will make a variety of recommendations for example to help practice therapy at home. One reason for doing this is that therapy can then happen wherever the child is and more frequently than can happen when a child is just seen in the clinic. At present we know very little about how parents respond to these recommendations.

What is the purpose of the study?

The purpose of this study is to find out if certain questionnaires are suitable for use by parents whose child is receiving speech & language therapy. These questionnaires look at what parents do when they are given a recommendation and why (adherence) and how confident they are in carrying out the recommendation (self-efficacy). They will also explore your beliefs about your child's speech and language problem. In addition I would like to check the suitability of some questionnaires that look at how satisfied parents are with the speech & language therapy service in general. I am also interested in seeking your views on the questionnaires and your comments on your experience of completing them. I hope to use the information you provide in a larger study. This larger study will consider how parents engage with speech & language therapy, what the relationship between this and the child's progress is and also how this relates to parents satisfaction with SLT services. Understanding these relationships can help us improve the way we work with children and their parents. This study is being undertaken for educational purposes, as part of my PhD in Health Psychology.

Why have I been invited?

Your speech & language therapist has invited you to help in this study because your child who is under 5 has been referred to Lambeth speech & language therapy and is currently receiving intervention from a speech & language therapist. I will be inviting about 50 parents to complete the questionnaires and telephone interview and make comments on them.

Do I have to take part?

It is up to you to decide. After reading this information sheet and you are interested in taking part please complete the consent form and the questionnaires and return them in the prepaid envelopes provided. When I receive them I will then telephone you to complete the final questionnaire or at least arrange a time that is convenient for you to do so. You are welcome to ask any questions at any time, my contact details are provided. You are free to withdraw at any time, without giving a reason. This would not affect the care you or your child receives from Lambeth Community Health.

What will happen to me if I take part?

You will receive five short questionnaires to complete which should take about 40 minutes to complete, I will ask you to return these to me by post. Once I have received these I will then telephone you at a time convenient to you to complete the final questionnaire over the phone. The telephone interview will also last about 30 minutes.

I would like to record the telephone interview because it is often difficult to write everything down. The recording will be deleted after I have taken the information from it. I will make you a copy of the interview tape for you to keep, if you would like this.

Your speech and language therapist will not see any of your responses to the questionnaires nor will he/she have access to your interview. Your speech & language therapist will know if you have taken part in the study because I will be asking her to provide me with copies of the recommendations she has made.

I would also like to look at your child's health records. This will allow me to record the description of your child's difficulties, and any speech & language therapy received. All information about you and your child will be kept strictly confidential and will not contain information about your name or address.

Expenses and payments

You will not receive any payment for taking part in this research. Stamped addressed envelopes will be provided for you to return your questionnaires.

What will I have to do?

The questionnaires you will complete on your own will ask you a range of questions. For example asking about the recommendations made by the speech and language therapist; asking you about your confidence in completing them and also about your satisfaction with speech & language therapy services in general. They will also ask you some questions about your beliefs about your child's problem. Your views on completing the questionnaires will also be asked. This should take you about 40 minutes. During the telephone interview I will be asking you further questions about the recommendations made by the speech and language therapist. This interview will also last about 30 minutes. I will also ask you some relevant background questions about you and your family. For all the questions that you will be asked there are no right or wrong answers. I am interested in your personal views and experiences.

What are the possible disadvantages and risks of taking part?

The main inconvenience to you is the time spent completing the questionnaires and telephone interview. There is little or no anticipated risk in this study; however, some people may be uncomfortable or reluctant to answer some questions. Please remember that you do not have to take part in this study and that you are free to stop the telephone interview at any point or to withdraw from the study at any time without giving a reason. I will not pass this information onto anyone and this will not affect the standard of care your child receives.

What are the possible benefits of taking part?

I cannot promise the study will help you directly but the information I get from this study will help to improve our understanding of how parents engage with speech and language therapy and this may in turn assist us to provide a better service to families.

What if there is a problem?

Any concerns or complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes Part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the Information Sheet

What will happen if I don't want to carry on with the study?

You do not have to take part in this study and you are free to stop the telephone interview at any point or to withdraw from the study without giving a reason. I will not pass this information onto anyone and this will not affect the standard of care you or your child receives. If you withdraw from the study I will not use your questionnaires or interview in my report and will delete the sound copy of the interview.

What if there is a problem?

If you have a concern about any aspect of this study, you can speak to myself, the researcher (Penny Williams) or if you prefer to my supervisor (Dr Vicky Slonims on 020 7188 6238) who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Patient Liaison Service (PALS). Contact details: Tel: 0800 587 8078 (Monday-Friday, 9am-5pm) Fax: 020 3049 4355 Email pals@lambethpct.nhs.uk or write to: NHS Lambeth PALS, 1 Lower Marsh, London SE1 7NT.

Will my taking part in this study be kept confidential?

Please be assured that all information that is collected during the course of the research will be kept strictly confidential. Your name and address will NOT be recorded on the questionnaires so you cannot be recognised from them. For this reason I will ask you return the consent form and questionnaires in separate envelopes. The digital recordings of the telephone interview will be encrypted and saved directly onto an NHS computer or on my University computer. All the computers are password protected. The interviews will be typed up and the paper copies stored in a locked filing cabinet in the Psychology Department at Guy's Hospital. I will be the only person who will have access to the data and it will only be used for this study.

Involvement of the General Practitioner/Family doctor (GP) & Local Speech & Language Therapist

Your GP will not be informed of your decision to take part in this study unless you choose to tell them. Your child's SLT will know that you are involved but will not have access to any of your responses to the questionnaires nor will he/she have access to your interview.

What will happen to the results of the research study?

The results of the study will be published in academic journals. It will not be possible to identify you in any report or publication. If you would like a summary of the results please let me know and I will forward this to you on completion of the study.

Who is organising and funding the research?

This research is not funded by an external body. It is sponsored by Kings College London.

Who has reviewed this study?

This study has been reviewed by the Proportionate Review Sub-Committee of the East London 3 Research Ethics Committee.

Further information and contact details

If you have any queries please do not hesitate to contact the researcher:

Penny Williams 020 71880196 or email penny.williams@kcl.ac.uk

Appendix 7.6 consent form

**Department of Psychology (at Guy's)
Health Psychology Section**

5th Floor, Bermondsey Wing
Guy's Hospital
London SE1 9RT

Tel: 020 7188 0196 Fax: 020 7188 0184

TITLE: A pilot study to identify appropriate measures of adherence, satisfaction and self-efficacy for use with parents of young children receiving speech & language therapy (SLT) intervention.

CONSENT FROM

Name of Researcher: **Penny Williams**

Your Name: _____

Your Child's Name (who is receiving speech & language therapy) & their Date of Birth:

Your telephone number: _____

Please initial box

1. I confirm that I have read and understand the information sheet dated 3.3.11 (Version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without mine, my child's health care or our legal rights being affected. ☐

3. I give permission for my child's speech and language therapist in Lambeth Community Health to be told that I am taking part in this study. I understand that the therapist will NOT be informed of any of my answers to the questionnaires or telephone interview. ☐

4. I understand that the telephone interview will be recorded. I also understand that the audio recording will be deleted after the researcher taken the information from it. ☐

5. I understand that relevant sections of my child's health records held within Child Health in Lambeth Community Health may be looked at by individuals from Kings College London, from regulatory authorities or from the NHS Trust where it is relevant to my taking part in research. I give permission for these individuals to have access to my child's records. ☐

5. I agree to take part in the above study. ☐

Name of Participant Date Signature

Researcher Date Signature

Appendix 7.7 brief guidance for participants

Brief Guidance for Participants, attached to the front of the pack envelope.

Brief Guidance for Participants:

1. Read the Information Sheet.
2. Read & Sign the Consent form.
3. Put the consent form into the small envelope and post.
4. Complete ALL questionnaires.
5. Place the completed questionnaires in the large envelope & post.

Thank you again for agreeing to help!

Appendix 7.8 Reminder Poster for Speech and Language therapists



A pilot study to identify appropriate measures of adherence, illness perceptions, satisfaction and self-efficacy for use with parents of young children receiving speech & language therapy (SLT) intervention.

Appendix 7.9 record of recommendations

Speech & Language Therapy Record of Recommendations Sheet

Child's Name & DOB: _____

Please write down the all the recommendations you have given to parents in order to support their child's speech & language development. Please include all types of recommendations e.g. for home therapy practice, to attend universal groups, to contact another professional/organisation, to follow up on links to additional information. Please only include the recommendations made for **this** period of intervention.

Recommendation	Type (<i>to be completed by Penny Williams</i>)
1. Have a Special Time every day with your child.	A
2. Reduce distractions during play.	A
3. Get down to your child's level	A
4. Follow your child's lead.	A
5. Give your child positive feedback and reduce negative feedback.	A
6. Comment on their play using simple language	A
7. Reduce questions.	A
8. Hold objects up to your face to encourage eye contact.	A
9. Encourage pretend play.	A
10. Use everyday items in an imaginative way as toys.	A

Please copy this sheet if required retaining the participant number at the top.

Thank you

A Active self-help: Parent to initiate or engage in some form of active self-help strategy.

B Professional-nonpsychological: Consult with a professional other than a mental health professional.

C School-based: Involving the school, tutoring, or school academic-related programs.

D SLT services: Any type of speech & language Therapy or another SLT evaluation.

Appendix 7.10 Parent Feedback form

Parent Feedback

To help in assessing the suitability of this questionnaire for parents of children receiving SLT please rate your level of agreement with the following questions:

CIRCLE YOUR ANSWER

1. This questionnaire was easy to understand.

Strongly Disagree

Disagree

Neither agree or
disagree

Agree

Strongly Agree

2. It was easy to use the rating system when answering the questions.

Strongly
Disagree

Disagree

Neither agree or
disagree

Agree

Strongly Agree

3. The questions were relevant to my experience of SLT

YES

NO

If NO were there some questions I missed? Please explain your answer?

4. Each questionnaire adds different and important information

YES

NO

If NO please explain which questions you thought were not relevant, or what questions you feel should have been added

6. How long did it take you to complete this questionnaire?

Thank you again for your help.

Appendix 7.11 HRS II

Homework Rating Scale II Parent (HRS II P)

Instructions: many parents find ways to engage in activities with their child between therapy sessions in a way that suits them. This may differ from the way in which the activity was discussed with their therapist. This questionnaire asks about your activities from the last sessions. Below are some ways in which people have said that they have engaged and learned from their activities. Please read each question carefully, and for each of the statements, circle the **one response** that best applies to you.

<p>1. Quantity I was able to do the activity with my child</p> <ul style="list-style-type: none"> 0 not at all 1 a little 2 some 3 a lot 4 completely <p>2. Quality I was able to do the activity well</p> <ul style="list-style-type: none"> 0 not at all 1 a little 2 some 3 a lot 4 completely <p>3. Difficulty The activity was difficult for me</p> <ul style="list-style-type: none"> 0 not at all 1 a little 2 some 3 a lot 4 completely <p>4. Obstacles I experienced obstacles in doing the activity</p> <ul style="list-style-type: none"> 0 not at all 1 a little 2 some 3 a lot 4 completely <p>5. Comprehension I understood what to do for the activity</p> <ul style="list-style-type: none"> 0 not at all 1 a little 2 some 3 a lot 4 completely <p>6. Rationale The reason for doing the activity was clear to me</p> <ul style="list-style-type: none"> 0 not at all 1 a little 2 some 3 a lot 4 completely 	<p>7. Collaboration I had an active role in planning the activity</p> <ul style="list-style-type: none"> 0 not at all 1 a little 2 some 3 a lot 4 completely <p>8. Specificity The guidelines for carrying out the activity were specific</p> <ul style="list-style-type: none"> 0 not at all 1 a little 2 some 3 a lot 4 completely <p>9. Match with Therapy Goals The activity matched with my child's therapy goals</p> <ul style="list-style-type: none"> 0 not at all 1 a little 2 some 3 a lot 4 completely <p>10. Pleasure I enjoyed the activity</p> <ul style="list-style-type: none"> 0 not at all 1 a little 2 some 3 a lot 4 completely <p>11. Mastery I gained a sense of control over my child's problems</p> <ul style="list-style-type: none"> 0 not at all 1 a little 2 some 3 a lot 4 completely <p>12. Progress The activity helped with my child's progress in therapy</p> <ul style="list-style-type: none"> 0 not at all 1 a little 2 some 3 a lot 4 completely
---	---

Appendix 7.12 M-ATIF

Modified Adherence Telephone Interview Form-Speech & Language Therapy (M-ATIF-SLT)

" Hello is Mr/Mrs/Ms _____ available (ask for person that signed the consent form)? Hello Mr/Mrs/Ms _____, my name is Penny Williams, I'm a speech & language therapist in Lambeth and I am also a research student based at Kings College London. You recently agreed to help me with my research and completed and returned some questionnaires to me. Thank you again for that. As well as returning these you also agreed to complete one more questionnaire over the phone. Do you remember agreeing to this? (If yes, proceed to telephone interview, if not give more information using the patient information sheet to help the parent to remember what the study is about, length of phone interview etc.) You might remember that your speech & language therapist made several suggestions or recommendations both after your child's assessment and also during their intervention. I'd like to go over those recommendations and find out which of them have worked out for you and your child. I realise that not all of the suggestions or recommendations may have been helpful to you or that you may have run into problems in being able to follow through on the suggestions. After reading each recommendation I'll be asking you how important you felt this recommendation or suggestion was for you and your child. I'll then ask to what extent you were able to follow through on that specific suggestion or recommendation. Lastly I'll read through a list of things that may have gotten in the way of being able to follow through on the suggestion or recommendation. Does that make sense? (Answer any questions they have about the interview process.) Remember, this information is confidential. I will not tell the person who gave you these recommendations what you say today. All information that you give me today will be recorded by a number only, not by using names or any other identifying information. I will give you a chance at the end of my interview to ask any questions. Please also remember that if you need a break that is OK and just let me know. We can start again after a short time. I would also like to record the interview; this is because it is too difficult to write everything down. Can you confirm that you are happy for the interview to be recorded?"

TURN ON RECORDER

Subject # _____

Date phone interview completed _____

The first recommendation was:

Recommendation 1:

*On a scale of one to five, with 1 being "not important", 3 being "somewhat important" and 5 being "extremely important"; how important did you think this recommendation was?
(circle response)*

1
Not important

2

3
Somewhat
important

4

5
Extremely
important

Comments made by parent:

On a scale of one to five, with 1 being “not at all”, 3 being “somewhat” and 5 being “always”; please tell me how much you think you followed this recommendation?

(circle response)

1
Not at all

2

3
Somewhat

4

5
Always

Comments made by parent:

I will now read you a list of reasons some people have for not following recommendations. Please think about each reason and decide whether it was a reason you had for not following the recommendation, or if the item made it more difficult for you to follow the recommendation. If the reason was true for you please say “yes” and if the item was not a problem, please say “no”.

(Read each option to parent and circle response)

- | | | |
|--|-----|----|
| 1. Didn't think it would help | YES | NO |
| 2. No longer a problem | YES | NO |
| 3. Resources not available | YES | NO |
| 4. Transportation | YES | NO |
| 5. Time | YES | NO |
| 6. Forgot to do it | YES | NO |
| 7. My child didn't want to do it | YES | NO |
| 8. Was there any other reason that I didn't mention that made it more difficult for you to follow this recommendation? | | |

Now, I would like us to do the same thing with the remainder of the recommendations. First I will read you the recommendation then I will read you the list of reasons.

Form repeated as required per number of recommendations and completed with the following questions

7.10 MATIF Continued

Finally, I'd like to ask you some questions about your child's speech and language skills now. Have your child's speech and language skills changed since they were first assessed?

NO

YES-improved

YES-worsened

(If a parent indicates improvement say,) I'd like you to rate on a 5-point scales how much you think your child's speech and language skills have improved since they were first assessed with 1 being "a little better", 3 being "better", and 5 being "much better".

(circle response)

1	2	3	4	5
A little better		Better		Much better

Comments made by parent:

(If a parent indicates worsened say,) I'd like you to rate on a 5-point scales how much you think your child's speech and language skills have worsened since they were first assessed with 1 being "a little worse", 3 being "worse", and 5 being "much worse".

(circle response)

1	2	3	4	5
A little worse		Worse		Much worse

Comments made by parent:

(If child is attending a pre-school educational setting ask,) Has your child's teacher/nursery worker told you that your child's speech & language skills have changed?

NO

YES-improved

YES-worsened

(If a parent indicates improvement in pre-school say,) I'd like you to rate on a 5-point scale how much your child's teacher/nursery worker has told you that your child's speech and language skills have improved since they were first assessed with 1 being "a little better", 3 being "better", and 5 being "much better".

(circle response)

1	2	3	4	5
A little better		Better		Much better

Comments made by parent:

(If a parent indicates worsened in pre-school say,) *I'd like you to rate on a 5-point scale how much your child's teacher/nursery worker has told you that your child's speech and language skills have worsened since they were first assessed with 1 being "a little worse", 3 being "worse", and 5 being "much worse".*

(circle response)

1	2	3	4	5
A little worse		Worse		Much worse

Comments made by parent:

As you can see, one of the things I'm most interested in in this study is the things that get in the way of following recommendations that a therapist gives. What could have helped you follow the recommendations you were given?

Appendix 7.13 CSQ-8

Client Satisfaction Questionnaire (CSQ-8)

Please help us to improve by answering some questions about the help you have received. We are interested in your honest opinions, whether they are positive or negative. Please answer all the questions. We also welcome your comments and suggestions. Thank you very much we really appreciate your help.

CIRCLE YOUR ANSWER

1. How would you rate the quality of service you received?

4	3	2	1
Excellent	Good	Fair	Poor

2. Did you get the kind of service you wanted?

1	2	3	4
No, definitely not	No, not really	Yes, generally	Yes definitely

3. To what extent has our service met your needs?

4	3	2	1
Almost all of our needs have been met	Most of our needs have been met	Only a few of my needs have been met	None of my needs have been met

4. If a friend were in need of similar help, would you recommend our service to him or her?

1	2	3	4
No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely

5. How satisfied are you with the amount of help you received?

1	2	3	4
Quite satisfied	Indifferent or mildly satisfied	Mostly satisfied	Very satisfied

6. Have the services you received helped you deal more effectively with your problems?

4	3	2	1
Yes, they helped a great deal	Yes, they helped somewhat	No, they really didn't help	No, they seemed to make things worse

7. In an overall sense, how satisfied are you with the service you have received?

4	3	2	1
Very satisfied	Mostly Satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied

8. If you were to seek help again, would you come back to our service?

1	2	3	4
No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely

Appendix 7.14 CSPQ

Consumer Satisfaction with Speech & Language Therapy Services Parent Questionnaire (CSPQ-SLT)

Please help us to improve by answering some questions about the speech & language therapy (SLT) service you and your child have received. We are interested in your honest opinion, whether they are positive or negative. Please answer all the questions. Thank you very much we really appreciate your help.

CIRCLE YOUR ANSWERS

1. I was satisfied with the referral process.

Strongly Disagree Disagree No Opinion Agree Strongly Agree

2. The time it took to travel to the appointment was acceptable.

Strongly Disagree Disagree No Opinion Agree Strongly Agree

3. My child was seen for assessment within a reasonable period of time.

Strongly Disagree Disagree No Opinion Agree Strongly Agree

4. I was satisfied with the explanation of the assessment findings.

Strongly Disagree Disagree No Opinion Agree Strongly Agree

5. I understood the relationship between the assessment findings and my child's therapy goals.

Strongly Disagree Disagree No Opinion Agree Strongly Agree

6. I understood my role in providing a home therapy program to my child.

Strongly Disagree Disagree No Opinion Agree Strongly Agree

7. It is important for parents to work with their child in a SLT program.

Strongly Disagree Disagree No Opinion Agree Strongly Agree

8. I was directly involved in my child's therapy program.

Strongly Disagree Disagree No Opinion Agree Strongly Agree

9. Parent participation in the therapy program increases the chances of a child's success.

Strongly Disagree Disagree No Opinion Agree Strongly Agree

10. I received adequate help from the speech & language therapist in providing the home program.

Strongly Disagree Disagree No Opinion Agree Strongly Agree

11. I was provided with clear therapy goals and objectives for the home program.

Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree
-------------------	----------	------------	-------	----------------

12. The speech & language therapist demonstrated the activities to show me what I could do at home.

Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree
-------------------	----------	------------	-------	----------------

13. I was helped to find suitable therapy materials at home.

Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree
-------------------	----------	------------	-------	----------------

14. I was provided with a sufficient number of therapy sessions during the intervention program.

Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree
-------------------	----------	------------	-------	----------------

15. Appointments during therapy were suitably spaced.

Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree
-------------------	----------	------------	-------	----------------

16. The best therapy sessions are when the speech & language therapist works with the child and parent alone.

Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree
-------------------	----------	------------	-------	----------------

17. Therapy sessions should include parent group instruction.

Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree
-------------------	----------	------------	-------	----------------

18. Therapy results would be better if SLT & pre-school services were integrated.

Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree
-------------------	----------	------------	-------	----------------

19. I was satisfied with my child's progress during therapy.

Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree
-------------------	----------	------------	-------	----------------

20. I believe my child's speech & language improved as a result of the therapy.

Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree
-------------------	----------	------------	-------	----------------

21. Pre-school SLT services were adequate.

Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree
-------------------	----------	------------	-------	----------------

22. Considering everything, I was satisfied with the SLT service provided.

Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree
-------------------	----------	------------	-------	----------------

Appendix 7.15 SE-SLTR

Self-efficacy to follow recommendations made by speech & language therapy (SE-SLTR)

I am interested in the levels of your personal confidence in being able to follow the home-based recommendations made by your child's speech and language therapist to support your child's therapy.

I am confident that I can carry out the home-based activities with my child that were recommended by the speech & language therapist even if...

	Not at all confident			Maybe		Very confident	
a. I am tired	1	2	3	4	5	6	7
b. I am on holiday	1	2	3	4	5	6	7
c. My family/partner takes up much of my time	1	2	3	4	5	6	7
d. My child is tired	1	2	3	4	5	6	7
e. I have worries	1	2	3	4	5	6	7
f. I am unwell	1	2	3	4	5	6	7
g. My child is unwell	1	2	3	4	5	6	7
h. I have lots of other things to do	1	2	3	4	5	6	7
i. Friends/family are visiting	1	2	3	4	5	6	7

Appendix 7.16 IPQR-SLCN

Participant ID:

Date.....

ILLNESS PERCEPTIONS QUESTIONNAIRE FOR SPEECH LANGUAGE COMMUNICATION NEEDS (IPQR-SLCN)

Definitions:

Problem: means your child's speech language communication problem as a whole

Difficulties: means the different parts of your child's problems

YOUR VIEWS ABOUT YOUR CHILD'S COMMUNICATION PROBLEM

Listed below are a number of difficulties that your child may or may not have. Please indicate by circling Yes or No, whether your child has experienced any of these difficulties.

	POSSIBLE DIFFICULTIES YOUR CHILD MAY HAVE	My child has this difficulty		IF YES: This difficulty is related to my child's communication problem	
1	Repeats words or parts of words	Yes	No	Yes	No
2	Prolongs sounds e.g. ffffffffish	Yes	No	Yes	No
3	Doesn't speak clearly	Yes	No	Yes	No
4	Doesn't understand what is said to him/her e.g. doesn't follow instructions	Yes	No	Yes	No
5	Reduced vocabulary/has few words	Yes	No	Yes	No
6	Doesn't ask questions	Yes	No	Yes	No
7	Doesn't name objects	Yes	No	Yes	No
8	Doesn't put words together into sentences	Yes	No	Yes	No
9	Repeats what is said (when not asked to)	Yes	No	Yes	No
10	Has lost words he/she used to say	Yes	No	Yes	No
11	Doesn't use gestures	Yes	No	Yes	No
12	Is in his/her own world	Yes	No	Yes	No
13	Is over friendly e.g. will talk to complete strangers	Yes	No	Yes	No
14	Is shy	Yes	No	Yes	No
15	Has problems with eye contact	Yes	No	Yes	No
16	Doesn't share toys with other children	Yes	No	Yes	No
17	Dislikes being touched or held	Yes	No	Yes	No
18	Plays with objects repetitively or intensely	Yes	No	Yes	No
19	Rocks, flaps hands or makes other unusual movements	Yes	No	Yes	No
20	No fear of real dangers	Yes	No	Yes	No
21	Fussy eater	Yes	No	Yes	No
22	Sleep problems	Yes	No	Yes	No
23	Difficulties taking him/her on public transport	Yes	No	Yes	No
24	Is behind in his/her learning	Yes	No	Yes	No
25	Aggressive	Yes	No	Yes	No
26	Tantrums	Yes	No	Yes	No
27	Problems with attention/concentration	Yes	No	Yes	No
28	Impulsive, does things without thinking	Yes	No	Yes	No
29	Anxious/nervous/worried	Yes	No	Yes	No
30	Doesn't sit still	Yes	No	Yes	No

IPQR-SLCN VIEWS ABOUT YOUR CHILD'S PROBLEM

I am interested in your own personal views of how you see your child's communication problem.

Please indicate how much you agree or disagree with the following statements about your child's problem by ticking the appropriate box.

Definitions: **Treatment** means speech and language therapy intervention.

	VIEWS ABOUT YOUR CHILD'S PROBLEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	My child's problem will last a short time					
IP2	My child's problem is likely to be permanent rather than temporary.					
IP3	My child's problem will last a long time					
IP4	My child's difficulties will pass quickly					
IP5	I expect my child to have this problem for the rest of their life.					
IP6	My child's problem is serious.					
IP7c	My child's problem has major consequences on their life					
IP7p	My child's problem has major consequences on my life					
IP8c	My child's problem does not have much effect on their life					
IP8p	My child's problem does not have much effect on my life					
IP9c	My child's problem strongly affects the way others see my child					
IP9p	My child's problem strongly affects the way others see me					
IP10	My child's problem has serious financial consequences.					
IP11	My child's problem causes difficulties for those who are close to my child					
IP12c	There is a lot my child can do to control their difficulties					
IP12p	There is a lot I can do to control my child's difficulties					
IP13c	What my child does can determine whether their problem gets better or worse.					
IP13p	What I do can determine whether my child's problem gets better or worse.					
IP13s	What the speech & language therapist (SLT) does can determine whether my child's problem gets better or worse.					
IP14c	The course of my child's problem depends on my child .					
IP14p	The course of my child's problem depends on me .					
IP14s	The course of my child's problem depends on the speech and language therapist.					
IP15c	Nothing my child does will affect my their problem					
IP15p	Nothing I do will affect my child's problem					

IP15s	Nothing the speech & language therapist does will affect my child's problem					
IP16c	My child has the power to influence their problem					
IP16p	I have the power to influence my child's problem					
IP17c	My child's actions will have no effect on the outcome of their problem.					
IP17p	My actions will have no effect on the outcome of my child's problem.					
IP18	My child's problem will improve in time.					
IP19	There is little that can be done to improve my child's problem					
IP20	My child's treatment will be effective in curing my child's problem.					
IP21	The negative effects of my child's problem can be prevented (avoided) by my child's treatment.					
IP22	My child's treatment can control their illness					
IP23	There is nothing which can help my child's problem.					
IP24	My child's difficulties are puzzling to me					
IP25	My child's problem is a mystery to me.					
IP26	I don't understand my child's problem.					
IP27	My child's problem doesn't make any sense to me					
IP28	I have a clear picture or understanding of my child's problem.					
IP29	My child's difficulties change a great deal from day to day					
IP30	My child's difficulties come and go in cycles.					
IP31	My child's problem is very unpredictable					
IP32	My child goes through cycles in which his/her problem gets better and worse					
IP33	I get depressed when I think about my child's problem.					
IP34	When I think about my child's problem I get upset.					
IP35	My child's problem makes me feel angry					
IP36	My child's problem does not worry me					
IP37	My child having this problem makes me feel worried.					
IP38	My child's problem makes me fear for the future					

IPQR-SLCN CAUSES OF MY CHILD'S COMMUNICATION PROBLEM

I am interested in what you think may have been the cause of your child's problem. As people are very different, there is no correct answer for this question. I am most interested in your own views about the things that caused your child's problem rather than what others including doctors, speech and language therapists or family may have suggested to you. Below is a list of possible causes for your child's problem. Please indicate how much you agree or disagree that they were a cause of your child's problem by ticking the appropriate box.

	MY CHILD'S PROBLEM IS CAUSED:	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	By hereditary reasons: it runs in mine or my partners side of the family					
C2	By my child's personality					
C3	By my child's age					
C4	By my child's lack of experience with other children					
C5	By my child's emotional state					
C6	Because my child used a dummy/pacifier					
C7	Because my child was born with it					
C8	Because my child started school too early					
C9	By my own behaviour e.g. I didn't do enough/the right things					
C10	By my emotional state e.g. feeling down, lonely, anxious, empty.					
C11	Because of family changes e.g. moving house, marital breakup, unhappy home.					
C12	Because the family speaks more than one language at home.					
C13	By problems during pregnancy.					
C14	Because my child was born prematurely					
C15	By my child being in hospital for a long time					
C16	Because of the tube my child had in his/her throat					
C17	By my child's surgery					
C18	Because of a problem with my child's brain and nerves					
C19	By my child's hearing problems					
C20	Because my child has a problem with his/her tongue					
C21	By being given vaccinations e.g. MMR					
C22	Because it is God's will.					
C23	By stress or worry					
C24	By a germ or virus					
C25	By diet or eating habits					
C26	By chance or bad luck					
C27	Because of pollution in the environment					
C28	Because of accident or injury					

Below, please list in the order of importance, the three most important things that you now believe caused YOUR CHILD'S problem. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

1. _____
2. _____
3. _____

Appendix 7.17 SLTherapists Recruitment Feedback

Recruitment Feedback

Respondents: Five SLTherapists: A, B, C, D and E

1. What were the main challenges you experienced in recruiting?

A (complex needs) I feel that parents are asked to fill out lots of forms for lots of professionals they see (us included with PPI), so when I asked if they would be able to participate the response was often 'another questionnaire?'. My brain often feels at capacity when seeing families (remembering to gain all the information I need, listening to and retaining the information parents need to give me), and appointments are often joint with other professionals which adds to the length of the appointment and the complexity of info given and received (and sometimes to how emotional the appointment is), sometimes I forgot to give out the pack or it felt inappropriate to give it.

B (EY) Lack of appropriate parents! Vast majority of parents of children on caseload have English as a second language, literacy difficulties, CP concerns. Also the difficulties associated with the design of group initial Ax leaving you with 10-15 minutes per family to gain history, complete assessment, give feedback and write report meant there was no time to provide packs in this context.

C (EY) Families not being able to read/write or read/write in English. Not wanting to overwhelm families with too much information when you are already giving lots of info and possibly handouts regarding their child's speech and language difficulties. Needing to get them to complete other pieces of feedback (e.g. end of therapy evaluations, group assessment evaluation, PPI questionnaire) and not wanting to ask too much of them.

D (EY) Time, and remembering to do it. I tended to discuss it at the end of an appointment most of the time, and often at that point, children could be getting restless (which meant it was hard for parents to listen), or you felt that you were in a rush particularly if there had been a lot to discuss in a session or you had families waiting outside. I also did not feel comfortable giving them out in assessment.

E (EY) Main challenges were that it was quite lengthy so I was potentially too choosy about who I gave it to - I thought that only those parents I'd built up a good relationship with would complete the pack. And I'm only now in clinic 1 day a week which has meant I haven't seen as many children as I used to! And in all honesty I sometimes forgot (sorry!)

2. Were the regular emails helpful/not helpful? Annoying?!

A The e-mails were a good reminder to try again

B Yes, useful reminders!

C Yes- good to be reminded.

D Helpful, particularly because they were often positive.

E Regular emails were regular enough! But useful reminder.

3. Did you make use of the recruitment reminder poster? If not any reason why?

A I did not use the recruitment poster because on home visits and groups run in children's centres (all my appointments are in these locations) I was not able to display them

B Yes

C Yes

D I did. However, it probably wasn't as helpful as it could have been because I stuck it to the door. This prompted me to remember the packs just before I said goodbye to families, which wasn't always the best time.

E No I didn't use the poster as the brown envelopes were right by my computer - where I would have put the poster.

4. Was there anything you think that could be done to make recruiting easier?

A Maybe just send the packs directly to families by post?

B n/a

C Perhaps sending the packs to families so that they can see that it is separate from the work they are doing with the therapist.

D If I had stored packs in the room that may have helped, (more visibility). I think if we hadn't had our PPI fortnight in the midst of recruitment that would have helped as well. I felt with some new families it was too much to ask to ask them to do both. Maybe having a bit of competition between patches re who recruited the most - although equally incredibly unfair when there's a different demographic to recruit from. I think a number of families I saw went away with the best intentions of doing it, but family life got in the way. So maybe there's something there about being able to complete it on the spot.

E I didn't find it hard to recruit, other than I wasn't in clinic very much and many of the children I see on a regular basis are now the dyspraxics or stammerers - and are over 5!

5. any other comments welcome!

A n/a

B n/a

C n/a

D n/a

E n/a

APPENDICES: CHAPTER EIGHT

- Appendix 8.1 SLT Information Sheet
- Appendix 8.2 Consent to Contact Form
- Appendix 8.3 Sensitivity Analysis between mothers and fathers completing the questionnaires
- Appendix 8.4 Participant Information Sheet
- Appendix 8.5 GAS Sensitivity Analysis
- Appendix 8.6 Demographic Form
- Appendix 8.7 IPQR-SLCN
- Appendix 8.8 Sensitivity Analysis for Drop outs Post Interview 1

Appendix 8.1. SLT Information Sheet



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Tel: 020 7188 0196 Fax: 020 7188 0184

SPEECH & LANGUAGE THERAPIST INFORMATION SHEET (31.5.13)

TITLE: A pilot study to identify appropriate measures of adherence, satisfaction and self-efficacy for use with parents of young children receiving speech & language therapy (SLT) intervention.

Research Ethics Study Number: REC Ref 13/SC/0341 Protocol Reference: Version 1.0

Thank you for agreeing to support this research study. The following information should assist your understanding of what the research study is about and your role in the study. If you have any more questions I am very happy to discuss them with you.

Background

Speech & language therapists such as yourself often aim to involve parents in their child's speech & language therapy and will make a variety of recommendations for example to help practice therapy at home. One reason for doing this is that therapy can then happen wherever the child is and more frequently than can happen when a child is just seen in the clinic. At present we know very little about how parents respond to these recommendations but in studies of other kinds of health problems there is some suggestion that a person's beliefs and experiences can influence how they respond to treatment advice.

What is the purpose of the study?

The purpose of this study is to consider how parents engage with speech & language therapy, what the relationship between this and the child's progress is and also how this relates to parents beliefs about their child's problem, their personal circumstances and satisfaction with SLT services. Understanding these relationships can help us improve the way we work with children and their parents. This study is being undertaken for educational purposes, as part of my PhD in Health Psychology.

Why have I been asked?

As a speech & language therapist, you are currently working with children who are under 5 years of age, and who have been accepted for intervention by Guy's & St Thomas Community NHS Speech & Language Therapy. I will be asking you to seek consent from parents of all children who are new referrals to the Early Years Team within the department. I expect to recruit about 300 parents in order that approximately 200 will complete the questionnaires during two meetings with me over the course of 6 months.

What will I have to do?

At your first meeting with a parent whose child has been accepted for intervention by the SLT department I will ask you to obtain consent from the parent for me to telephone them to talk about my the research project. This will continue for the first 12 months of the study. The exceptions are:

- A child over the age of 5.0 years at their first appointment with speech & language therapy

- A child with a chronic or current medical illness.
- A child who is seen primarily for eating and drinking difficulties.
- A child who is subject to a child protection enquiry or is a 'Looked After' child.
- A parent who requires the use of interpreting services.

Parents will have received a copy of the study information pack along with their first appointment letter. This pack contains a covering letter to parents, a parent information sheet and a consent form.

Following my telephone call to them, if parents give their consent to participate they will be asked to meet with me on two occasions to complete a number of different questionnaires. During the first meeting, completing the questionnaires should take approximately an hour and fifteen minutes. I will then telephone the parent to arrange the final meeting which will take place approximately six months later; the questionnaires in this final meeting should take up to an hour and forty five minutes to complete.

Prior to the second meeting with parents I will contact you to request a copy of the recommendations you made for this parent and their child. I have enclosed a 'recommendation sheet' for you to use for this purpose. I will also asking you to forward copies of the results of the standardised assessment of SLCN that you have carried out with a child and copies of their completed Goal Attainment Scales. These can be emailed to me using nhs.net email or sent via internal mail. To maintain confidentiality the 'recommendation sheet' will have a code rather than the name of the parent of child and I will transfer the assessment results into a database assigning the same code and will subsequently destroy any copies with any patient identifying data.

I will also be asking parents for their consent to look at their child's health records. This will allow me to record the description of their child's difficulties, and any speech & language therapy received. All information about parents and their child will be kept strictly confidential and will not contain information about their name or address.

What will the parents have to do?

Parents will be asked to meet with me on two occasions to complete a number of different questionnaires. They can decide where we meet for example their home or at the clinic where their child receives speech and language therapy. During the first meeting, completing the questionnaires should take approximately an hour and fifteen minutes. I will then telephone the parent to arrange the final meeting which will take place approximately six months later; the questionnaires in this final meeting should take up to an hour and forty five minutes to complete.

The questionnaires the parents will complete on their own will ask a range of questions. For example, asking about the recommendations made by the speech and language therapist; asking parents about their confidence in completing them and also about their beliefs about, and satisfaction with, speech & language therapy services in general. They will also ask some questions about parents beliefs about their child's problem, about parenting in general and ask for some information about their personal circumstances such as some relevant background questions about you and your family. Parents will be advised that for all the questions there are no right or wrong answers and that I am interested in their personal views and experiences.

What will happen if parents don't want to carry on with the study?

Parents do not have to take part in this study and are free to stop at any point during either meeting or to withdraw from the study without giving a reason. They will be told that I will not pass this information onto anyone and that this will not affect the standard of care they or their child receives. If a parent withdraws from the study I will not use their questionnaires.

What if there is a problem?

If you have a concern about any aspect of this study, you can speak to myself, the researcher (Penny Williams) or if you prefer to my supervisor (Dr Vicky Slonims on 020 7188 6238) who will do their best to answer your questions.

Will the information given by myself and the parents be kept confidential?

All information that is collected during the course of the research will be kept strictly confidential. The parents name and address will NOT be recorded on the questionnaires so they cannot be recognised from them. The data from the questionnaires, child recommendations and assessment results will be transferred onto my University computer and the paper copies stored in a locked filing cabinet in the Psychology Department at Guy's Hospital. My computer is password protected.

Will I get to see the answers to the questionnaires for the parents I am working with?

You will know which parents are involved because I will ask you for a copy of the recommendations you made for them and their assessment results but will you will not have access to any of the detailed responses to the questionnaires.

What will happen to the results of the research study?

The results of the study will be published in academic journals. It will not be possible to identify parents in any report or publication. If you would like a summary of the results please let me know and I will forward this to you on completion of the study.

Who is organising and funding the research?

This research is not funded by an external body. It is sponsored by Kings College London.

Further information and contact details

If you have any queries please do not hesitate to contact me: **Penny Williams** 020 71880196 or email penny.williams@kcl.ac.uk or penny.williams@lambethpct.nhs.uk

**Penny's research: Consent for contact
Instructions for SLTs at initial assessment**

Please ask each parent that meets the inclusion/exclusion criteria (check list attached to file) for their signed consent to allow me to telephone them about the research. You may find the short script below helpful.

"Along with your letter telling you about this appointment you were also sent some information about a research study. This research is being carried out by a colleague, Penny Williams, in my department and she would like me to ask for your permission to give you a call to talk about the research, is that OK? Would you mind just signing this form to confirm this so I can let her know? All this means is that she will ring you it doesn't mean that you are agreeing to take part, you can do that later if you want to."

If they ask about the study, keep it simple at this point, you could say:

" As I understand it the research is looking at how parents of young children engage with speech & language therapy, and will be considering what the relationship between this and a child's progress is and also how this relates to parents beliefs about their child's problem, their personal circumstances and satisfaction with SLT services. Understanding these relationships can help us improve the way we work with children and their parents. All you will be asked to do is meet with Penny on two occasions to answer some questions but she will talk more about this when she rings you."

Appendix 8.2 Consent to Contact Form



Department of Psychology (at Guy's)

Health Psychology Section

5th Floor, Bermondsey Wing

Guy's Hospital

London SE1 9RT

Tel: 020 7188 0196 Fax: 020 7188 0184

TITLE: Parents and Speech and Language Therapy for young children.

Basic Study Information (Please also refer to the Information Sheet sent to you in the post)

Participating in this study would mean meeting with the researcher twice, the first meeting should take approximately an hour and fifteen minutes, the second interview, approximately six months later, should take up to an hour and forty five minutes.

CONSENT FOR TELEPHONE CONTACT FROM

Name of Researcher: **Penny Williams**

Your Name: _____

Your Child's Name (who is receiving speech & language therapy) & their Date of Birth:

Your telephone number: _____

Please initial box

I confirm that I give my consent for Penny Williams to telephone me to discuss this study.

☐

Name of Participant

Date

Signature

Appendix 8.3 Sensitivity Analysis between mothers and fathers completing the questionnaires

Independent Samples Test										
		Levene's Test		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error	95% Confidence Interval	
									Lower	Upper
Deprivation score	Equal variances (EV) assumed	.93	0.93	0.34	-0.15	192.0	0.88	-0.43	2.89	-6.13
	EV not assumed				-0.18	9.14	0.86	-0.43	2.47	-6.00
Child age	EV assumed	.04	0.04	0.85	-1.67	197.0	0.10	-5.53	3.31	-12.05
	EV not assumed				-1.85	8.97	0.10	-5.53	2.99	-12.29
Mother age	EV assumed	.66	0.66	0.42	0.18	191.0	0.86	0.38	2.13	-3.82
	EV not assumed				0.16	7.44	0.88	0.38	2.47	-5.39
Total languages spoken	EV assumed	.25	0.25	0.62	0.11	195.0	0.91	0.02	0.22	-0.40
	EV not assumed				0.10	8.58	0.92	0.02	0.25	-0.54
Maternal education	EV assumed	.01	0.01	0.94	0.58	196.0	0.56	0.28	0.49	-0.68
	EV not assumed				0.58	8.78	0.58	0.28	0.49	-0.82
No. SLTs	EV assumed	1.44	1.44	0.23	-0.88	197.00	0.38	-0.23	0.26	-0.74
	EV not assumed				-0.69	8.45	0.51	-0.23	0.33	-0.98
No. Intervention Types	EV assumed	.09	0.09	0.76	0.55	197.00	0.58	0.13	0.24	-0.35
	EV not assumed				0.54	8.75	0.60	0.13	0.25	-0.43
No. SLCN descriptors	EV assumed	.00	0.00	0.99	-0.30	197.0	0.76	-0.05	0.18	-0.41
	EV not assumed				-0.31	8.79	0.77	-0.05	0.18	-0.46
% nonattendance	EV assumed	.08	0.08	0.77	0.21	197.0	0.83	1.49	7.06	-12.44
	EV not assumed				0.22	8.86	0.83	1.49	6.75	-13.81
FLQ child comm	EV assumed	.22	0.22	0.64	-0.04	197.0	0.97	-0.04	1.00	-2.01
	EV not assumed				-0.03	8.57	0.98	-0.04	1.15	-2.66
FLQ Family impact	EV assumed	1.18	1.18	0.28	0.59	197.0	0.56	1.24	2.11	-2.93
	EV not assumed				0.73	9.28	0.48	1.24	1.69	-2.58

FLQ confidence	EV assumed	.08	0.08	0.78	-1.18	197.0	0.24	-1.94	1.64	-5.18
	EV not assumed				-1.17	8.75	0.27	-1.94	1.66	-5.72
FLQ child social	EV assumed	3.43	3.42	0.07	0.19	197.0	0.85	0.31	1.59	-2.83
	EV not assumed				0.28	9.78	0.79	0.31	1.11	-2.17
FLQ TX Experience	EV assumed	1.44	1.44	0.23	-0.95	197.0	0.34	-0.98	1.03	-3.01
	EV not assumed				-1.30	9.59	0.22	-0.98	0.75	-2.66
FLQTotal	EV assumed	2.19	2.19	0.14	-0.27	197.0	0.79	-1.42	5.27	-11.81
	EV not assumed				-0.42	10.21	0.68	-1.42	3.34	-8.85
SEPTI Emot.avail	EV assumed	3.18	3.17	0.08	1.44	197.0	0.15	1.95	1.35	-0.71
	EV not assumed				2.69	11.38	0.02	1.95	0.72	0.36
SEPTI Nurture	EV assumed	.08	0.08	0.77	0.93	197.0	0.35	0.99	1.06	-1.10
	EV not assumed				1.00	8.92	0.34	0.99	0.98	-1.24
SEPTI Discipline	EV assumed	.14	0.14	0.71	0.20	197.0	0.84	0.31	1.51	-2.67
	EV not assumed				0.22	8.89	0.83	0.31	1.42	-2.91
SEPTIO Play	EV assumed	.40	0.40	0.53	0.60	197.0	0.55	1.05	1.74	-2.38
	EV not assumed				0.56	8.66	0.59	1.05	1.87	-3.21
SEPTI Teach	EV assumed	.04	0.04	0.85	0.99	197.0	0.32	2.05	2.06	-2.01
	EV not assumed				1.00	8.78	0.34	2.05	2.05	-2.61
SEPTI Icare	EV assumed	.002	0.00	0.96	0.56	197.0	0.58	1.11	1.99	-2.82
	EV not assumed				0.55	8.77	0.59	1.11	2.00	-3.44
SEPTI TOTAL	EV assumed	.21	0.21	0.65	0.87	197.0	0.39	6.37	7.36	-8.14
	EV not assumed				1.02	9.12	0.33	6.37	6.24	-7.71
Se-SLTR total	EV assumed	.10	0.10	0.75	0.65	197.0	0.51	1.83	2.80	-3.69
	EV not assumed				0.55	8.53	0.60	1.83	3.32	-5.75
PETS credibility	EV assumed	.01	0.01	0.94	-0.37	197.0	0.71	-0.53	1.44	-3.37
	EV not assumed				-0.41	8.94	0.69	-0.53	1.32	-3.52
PETS child improvement	EV assumed	.01	0.01	0.94	-0.05	197.0	0.96	-0.06	1.27	-2.58
	EV not assumed				-0.05	8.76	0.96	-0.06	1.29	-2.99

PETS parents involvement	EV assumed	.25	0.25	0.62	-0.66	197.0	0.51	-0.39	0.59	-1.55
	EV not assumed				-0.69	8.85	0.51	-0.39	0.57	-1.68
PETS Total	EV assumed	.39	0.39	0.53	-0.01	197.0	0.99	-0.03	2.69	-5.34
	EV not assumed				-0.01	8.65	0.99	-0.03	2.91	-6.67
FOCUS Baseline	EV assumed	3.40	3.40	0.07	-0.99	197.0	0.32	-19.38	19.64	-58.12
	EV not assumed				-1.63	10.47	0.13	-19.38	11.92	-45.78
IPQRID ext. behav	EV assumed	1.44	1.44	0.23	1.11	197.0	0.27	0.53	0.48	-0.41
	EV not assumed				1.28	9.07	0.23	0.53	0.41	-0.40
IPQRID Lang	EV assumed	1.06	1.06	0.30	0.71	197.0	0.48	0.28	0.40	-0.51
	EV not assumed				0.74	8.87	0.48	0.28	0.38	-0.58
IPQRid other	EV assumed	.77	0.76	0.38	0.49	197.0	0.63	0.15	0.31	-0.46
	EV not assumed				0.60	9.23	0.56	0.15	0.25	-0.42
IPQRid Soc.comm. ASD	EV assumed	.34	0.34	0.56	1.16	197.0	0.25	0.39	0.33	-0.27
	EV not assumed				1.28	8.97	0.23	0.39	0.30	-0.30
IPQRid sum	EV assumed	.05	0.05	0.83	1.35	197.0	0.18	2.26	1.67	-1.04
	EV not assumed				1.41	8.86	0.19	2.26	1.60	-1.37
IPQRid NOT Related SUM	EV assumed	.92	0.92	0.34	1.56	197.0	0.12	1.63	1.04	-0.43
	EV not assumed				1.93	9.24	0.09	1.63	0.85	-0.28
IPQR Timeline	EV assumed	.69	0.69	0.41	0.58	197.0	0.56	0.87	1.50	-2.08
	EV not assumed				0.68	9.13	0.51	0.87	1.27	-1.99
IPQR Consequences	EV assumed	.97	0.97	0.33	-0.20	197.0	0.85	-0.48	2.45	-5.31
	EV not assumed				-0.24	9.28	0.81	-0.48	1.96	-4.89
IPQR Conseq.Child	EV assumed	.81	0.81	0.37	-0.75	197.0	0.45	-0.75	0.99	-2.71
	EV not assumed				-0.95	9.31	0.37	-0.75	0.79	-2.53
IPQR Conseq. Parent	EV assumed	1.15	1.15	0.29	-0.60	197.0	0.55	-0.53	0.89	-2.28
	EV not assumed				-0.75	9.26	0.47	-0.53	0.72	-2.14
IPQR Personal Control	EV assumed	.01	0.01	0.91	0.05	197.0	0.96	0.09	1.95	-3.74
	EV not assumed				0.05	8.92	0.96	0.09	1.80	-4.00

IPQR Control Child	EV assumed	.18	0.18	0.68	1.51	197.0	0.13	2.01	1.33	-0.62
	EV not assumed				1.82	9.19	0.10	2.01	1.10	-0.48
IPQR Control Parent	EV assumed	.01	0.01	0.92	-1.34	197.0	0.18	-1.92	1.43	-4.73
	EV not assumed				-1.29	8.71	0.23	-1.92	1.48	-5.29
IPQR Treatment Control	EV assumed	.001	0.00	0.98	-0.98	197.0	0.33	-0.85	0.87	-2.58
	EV not assumed				-0.96	8.75	0.36	-0.85	0.89	-2.86
IPQR Coherence	EV assumed	.08	0.08	0.78	-1.59	197.0	0.11	-1.99	1.25	-4.45
	EV not assumed				-1.49	8.67	0.17	-1.99	1.33	-5.02
IPQR Timeline Cyclical	EV assumed	1.69	1.69	0.20	0.76	197.0	0.45	0.88	1.15	-1.40
	EV not assumed				0.98	9.37	0.35	0.88	0.90	-1.14
IPQR Emot. representations	EV assumed	1.34	1.34	0.25	1.59	197.0	0.11	2.72	1.71	-0.65
	EV not assumed				2.06	9.39	0.07	2.72	1.32	-0.25
IPQR external cause	EV assumed	.30	0.30	0.58	-0.88	196.0	0.38	-0.97	1.10	-3.14
	EV not assumed				-0.71	8.48	0.50	-0.97	1.36	-4.08
IPQR Self-blame cause	EV assumed	.27	0.27	0.61	1.48	196.0	0.14	1.24	0.83	-0.41
	EV not assumed				1.65	9.00	0.13	1.24	0.75	-0.45
IPQR Early medical cause	EV assumed	.05	0.05	0.83	0.99	196.0	0.32	1.03	1.04	-1.02
	EV not assumed				1.00	8.79	0.34	1.03	1.03	-1.31
IPQR child-related cause	EV assumed	.63	0.63	0.43	1.30	196.0	0.20	1.01	0.78	-0.52
	EV not assumed				0.99	8.42	0.35	1.01	1.02	-1.32
IPQR no. cause	EV assumed	.24	0.24	0.62	0.66	197.0	0.51	0.79	1.19	-1.56
	EV not assumed				0.83	9.30	0.43	0.79	0.95	-1.35

Appendix 8.4 Participant Information Sheet



Department of Psychology (at Guy's)

Health Psychology Section

5th Floor, Bermondsey Wing

Guy's Hospital

London SE1 9RT

Tel: 020 7188 0196 Fax: 020 7188 0184

PARTICIPANT INFORMATION SHEET (24.6.13)

TITLE: Parents and Speech and Language Therapy for young children.

Research Ethics Study Number: REC Ref 13/SC/0341

Protocol Reference: Version

1.0

I am inviting you to take part in my study exploring parent's beliefs about their child's speech language communication needs. Before you decide you may find it helpful to consider the information below.

Study Background & Purpose

Speech & language therapists often aim to involve parents in their child's speech & language therapy and will make a variety of recommendations to help practice therapy at home. At present we know very little about how parents respond to these recommendations but in studies of other kinds of health problems there is some suggestion that a person's beliefs and experiences can influence how they respond to treatment advice. This study aims to consider how parents participate in speech & language therapy, what the relationship between this and the child's progress is and also how this relates to parents beliefs about their child's problem, their personal circumstances and satisfaction with SLT services. Understanding these relationships can help us improve the way we work with children and their parents.

Why have I been invited?

You have been invited because your child, who is under 5 years of age, has been accepted for intervention by Guy's & St Thomas Community NHS Speech & Language Therapy and you are their main carer who will be attending speech and language therapy and carrying out the home practice with your child. I will be inviting about 300 parents to participate in the study.

What will happen to me if I take part?

You will meet with me on two occasions to complete a number of different questionnaires; where we meet is up to you, it could be your home or at the clinic where your child receives speech and language therapy. Our first meeting should take approximately an hour and fifteen minutes. Approximately six months later I will then telephone you to arrange the final meeting which should take up to an hour and forty five minutes.

During the meetings I will ask you to complete a variety of questionnaires which will consider a number of areas. These include asking about the recommendations made by the speech and language therapist; asking you about your confidence in completing them and also about your beliefs about, and satisfaction with, speech & language therapy services in general. Others include asking about your beliefs about your child's problem, about parenting in general and ask for some background information about you and your family. For all the questions that you will be asked there are no right or wrong answers. I am interested in your personal views and experiences.

Your speech and language therapist will know that you have taken part in the study because I will be asking them to provide me with copies of the recommendations they have made for your child and copies of your child's assessment results. They will NOT see any of your responses to the questionnaires completed in your meetings with me. I would also like to look at your child's health records to allow me to record the description of your child's difficulties, and any speech & language therapy received.

What are the possible benefits of taking part?

This study will help to improve our understanding of how parents engage with speech and language therapy and this may in turn assist us to provide a better service to families. There are no anticipated risks to taking part, although the inconvenience to you in terms of your time is a disadvantage. You will not receive any payment for taking part in this research.

What will happen if I don't want to carry on with the study?

You do not have to take part in this study and you are free to withdraw from the study at any time without giving a reason. This decision would not affect the care you or your child receives from Guy's & St Thomas Community NHS. If you decide to withdraw from the study I will not use your questionnaires in my report.

What if there is a problem?

If you have a concern about any aspect of this study, you can speak to myself, the researcher (Penny Williams) or if you prefer to my supervisor (Dr Vicky Slonims on 020 7188 6238) who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Patient Liaison Service (PALS). Contact details: TELEPHONE: 020 7188 8801 or 020 7188 8803 EMAIL pals@gstt.nhs.uk or write to: PALS, c/o

KIC, Ground floor, North Wing, St Thomas' Hospital, Westminster Bridge Road, London SE1 7EH. WEBSITE:

<http://www.guysandstthomas.nhs.uk/patients-and-visitors/patients/your-care/patient-info-team/pals.aspx>

Will my taking part in this study be kept confidential?

Please be assured that all information that is collected during the course of the research will be kept strictly confidential. Your name and address will NOT be recorded on the questionnaires so you cannot be recognised from them. The data from the questionnaires will be transferred onto my University computer and the paper copies stored in a locked filing cabinet in the Psychology Department at Guy's Hospital. My computer is password protected. I will be the only person who will have access to the data and it will only be used for this study.

What will happen to the results of the research study?

The results of the study will be published in academic journals. If you would like a summary of the results please let me know and I will forward this to you on completion of the study.

This study is being undertaken for educational purposes, as part of my PhD in Health Psychology. It is sponsored by Kings College London and it has been reviewed by the South Central Oxford-C Research Ethics Committee.

If you have any queries please do not hesitate to contact the researcher: **Penny Williams** 020 71880196 or email penny.williams@kcl.ac.uk

Appendix 8.5 GAS Sensitivity Analysis

Independent Samples Test										
		Levene's Test for		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval	
									Lower	Upper
Deprivation score	Equal variances assumed	0.01	0.91	0.85	197.0	0.40	1.17	1.38	-1.55	3.90
	Equal variances not assumed			0.85	196.9	0.40	1.17	1.38	-1.55	3.89
Child age	Equal variances assumed	0.07	0.79	1.28	192.0	0.20	1.55	1.21	-0.84	3.94
	Equal variances not assumed			1.28	191.4	0.20	1.55	1.21	-0.84	3.94
Mother age	Equal variances assumed	1.45	0.23	1.54	191.0	0.13	1.30	0.84	-0.37	2.96
	Equal variances not assumed			1.54	191.0	0.13	1.30	0.84	-0.36	2.96
Maternal Education	Equal variances assumed	0.00	0.99	-1.20	196.0	0.23	-0.24	0.20	-0.64	0.16
	Equal variances not assumed			-1.20	194.0	0.23	-0.24	0.20	-0.64	0.16
No. SLTs	Equal variances assumed	5.63	0.02	0.84	197.0	0.40	0.09	0.11	-0.12	0.30
	Equal variances not assumed			0.85	194.3	0.40	0.09	0.11	-0.12	0.30
No. Intervention Types	Equal variances assumed	1.69	0.20	4.14	197.0	0.00	0.40	0.10	0.21	0.59
	Equal variances not assumed			4.15	196.9	0.00	0.40	0.10	0.21	0.59
No. SLCN descriptors	Equal variances assumed	0.69	0.41	5.37	197.0	0.00	2.24	0.42	1.42	3.07
	Equal variances not assumed			5.38	197.0	0.00	2.24	0.42	1.42	3.07
% nonattendance	Equal variances assumed	11.53	0.00	-3.08	197.0	0.00	-8.84	2.87	-14.50	-3.18
	Equal variances not assumed			-3.05	171.8	0.00	-8.84	2.90	-14.57	-3.11
FLQ child comm	Equal variances assumed	4.01	0.05	0.76	197.0	0.45	0.32	0.42	-0.50	1.14
	Equal variances not assumed			0.77	196.8	0.44	0.32	0.41	-0.50	1.13
FLQ Family impact	Equal variances assumed	0.07	0.79	0.35	197.0	0.73	0.31	0.88	-1.43	2.04
	Equal variances not assumed			0.35	194.5	0.73	0.31	0.88	-1.43	2.05
FLQ confidence	Equal variances assumed	0.14	0.71	0.84	197.0	0.40	0.57	0.68	-0.78	1.92
	Equal variances not assumed			0.84	197.0	0.40	0.57	0.68	-0.77	1.92

FLQ child social	Equal variances assumed	0.18	0.67	0.84	197.0	0.40	0.56	0.66	-0.75	1.86
	Equal variances not assumed			0.84	196.6	0.40	0.56	0.66	-0.74	1.86
FLQ TX Experience	Equal variances assumed	0.22	0.64	-0.69	197.0	0.49	-0.30	0.43	-1.14	0.55
	Equal variances not assumed			-0.69	194.8	0.49	-0.30	0.43	-1.14	0.55
FLQTotal	Equal variances assumed	6.26	0.01	0.67	197.0	0.51	1.46	2.19	-2.86	5.78
	Equal variances not assumed			0.67	193.2	0.50	1.46	2.17	-2.83	5.74
IPQRID ext. behav	Equal variances assumed	0.00	0.97	-1.94	197.0	0.05	-0.38	0.20	-0.77	0.01
	Equal variances not assumed			-1.94	196.0	0.05	-0.38	0.20	-0.77	0.01
IPQRID Lang	Equal variances assumed	5.69	0.02	-0.23	197.0	0.82	-0.04	0.17	-0.37	0.29
	Equal variances not assumed			-0.24	196.4	0.81	-0.04	0.17	-0.37	0.29
IPQRId other	Equal variances assumed	0.72	0.40	-0.88	197.0	0.38	-0.11	0.13	-0.36	0.14
	Equal variances not assumed			-0.87	193.6	0.38	-0.11	0.13	-0.36	0.14
IPQRId Soc.comm. ASD	Equal variances assumed	0.15	0.70	-0.41	197.0	0.68	-0.06	0.14	-0.33	0.22
	Equal variances not assumed			-0.41	194.9	0.68	-0.06	0.14	-0.33	0.22
IPQRId sum	Equal variances assumed	3.59	0.06	-1.20	197.0	0.23	-0.83	0.70	-2.21	0.54
	Equal variances not assumed			-1.20	195.9	0.23	-0.83	0.69	-2.20	0.53
IPQRId NOT Related SUM	Equal variances assumed	6.97	0.01	-3.36	197.0	0.00	-1.43	0.42	-2.26	-0.59
	Equal variances not assumed			-3.32	170.3	0.00	-1.43	0.43	-2.28	-0.58
IPQR Timeline	Equal variances assumed	0.58	0.45	0.89	197.0	0.38	0.55	0.62	-0.67	1.78
	Equal variances not assumed			0.89	196.2	0.37	0.55	0.62	-0.67	1.78
IPQR Consequences	Equal variances assumed	1.72	0.19	1.46	197.0	0.15	1.48	1.01	-0.52	3.48
	Equal variances not assumed			1.47	196.7	0.14	1.48	1.01	-0.51	3.47
IPQR Conseq.Child	Equal variances assumed	0.34	0.56	1.89	197.0	0.06	0.78	0.41	-0.03	1.59
	Equal variances not assumed			1.90	196.9	0.06	0.78	0.41	-0.03	1.59
IPQR Conseq. Parent	Equal variances assumed	0.65	0.42	1.25	197.0	0.21	0.46	0.37	-0.27	1.18
	Equal variances not assumed			1.25	196.7	0.21	0.46	0.37	-0.26	1.18
IPQR Personal Control	Equal variances assumed	0.16	0.69	-0.10	197.0	0.92	-0.08	0.81	-1.67	1.52
	Equal variances not assumed			-0.10	194.9	0.92	-0.08	0.81	-1.68	1.52

IPQR Control Child	Equal variances assumed	1.18	0.28	1.22	197.0	0.23	0.68	0.56	-0.42	1.77
	Equal variances not assumed			1.21	190.4	0.23	0.68	0.56	-0.43	1.78
IPQR Control Parent	Equal variances assumed	3.32	0.07	-1.27	197.0	0.21	-0.75	0.59	-1.93	0.42
	Equal variances not assumed			-1.26	185.1	0.21	-0.75	0.60	-1.93	0.42
IPQR Treatment Control	Equal variances assumed	0.33	0.57	-1.45	197.0	0.15	-0.53	0.36	-1.24	0.19
	Equal variances not assumed			-1.45	195.4	0.15	-0.53	0.36	-1.24	0.19
IPQR Coherence	Equal variances assumed	0.75	0.39	-0.29	197.0	0.77	-0.15	0.52	-1.19	0.88
	Equal variances not assumed			-0.29	192.2	0.77	-0.15	0.52	-1.19	0.88
IPQR Timeline Cyclical	Equal variances assumed	0.17	0.68	-0.39	197.0	0.70	-0.19	0.48	-1.13	0.76
	Equal variances not assumed			-0.39	195.8	0.70	-0.19	0.48	-1.13	0.76
IPQR Emot. representations	Equal variances assumed	0.66	0.42	0.12	197.0	0.90	0.09	0.72	-1.32	1.50
	Equal variances not assumed			0.12	196.9	0.90	0.09	0.72	-1.32	1.50
IPQR external cause	Equal variances assumed	0.03	0.86	-0.28	196.0	0.78	-0.13	0.46	-1.04	0.78
	Equal variances not assumed			-0.28	195.3	0.78	-0.13	0.46	-1.04	0.78
IPQR Self-blame cause	Equal variances assumed	0.02	0.90	-0.58	196.0	0.56	-0.20	0.35	-0.89	0.49
	Equal variances not assumed			-0.58	194.6	0.56	-0.20	0.35	-0.89	0.49
IPQR Early medical cause	Equal variances assumed	0.05	0.83	-1.22	196.0	0.23	-0.53	0.43	-1.38	0.33
	Equal variances not assumed			-1.22	194.3	0.23	-0.53	0.43	-1.38	0.33
IPQR child-related cause	Equal variances assumed	0.37	0.54	-0.20	196.0	0.84	-0.07	0.32	-0.71	0.57
	Equal variances not assumed			-0.20	192.7	0.84	-0.07	0.33	-0.71	0.58
IPQR no. cause	Equal variances assumed	0.01	0.93	-0.77	197.0	0.44	-0.38	0.50	-1.36	0.60
	Equal variances not assumed			-0.77	186.6	0.44	-0.38	0.50	-1.36	0.60
SEPTI Emot.avail	Equal variances assumed	2.07	0.15	-2.41	197.0	0.02	-1.34	0.56	-2.43	-0.24
	Equal variances not assumed			-2.43	193.7	0.02	-1.34	0.55	-2.43	-0.25
SEPTI Nurture	Equal variances assumed	0.95	0.33	-0.87	197.0	0.39	-0.38	0.44	-1.25	0.48
	Equal variances not assumed			-0.87	196.5	0.38	-0.38	0.44	-1.25	0.48
SEPTI Discipline	Equal variances assumed	0.32	0.57	-0.39	197.0	0.69	-0.25	0.63	-1.48	0.99
	Equal variances not assumed			-0.39	196.4	0.69	-0.25	0.62	-1.48	0.98

SEPTIO Play	Equal variances assumed	3.32	0.07	-1.88	197.0	0.06	-1.35	0.72	-2.76	0.06
	Equal variances not assumed			-1.89	195.4	0.06	-1.35	0.71	-2.75	0.06
SEPTI Teach	Equal variances assumed	2.10	0.15	-0.40	197.0	0.69	-0.34	0.86	-2.03	1.35
	Equal variances not assumed			-0.40	196.9	0.69	-0.34	0.86	-2.03	1.35
SEPTI Icare	Equal variances assumed	0.02	0.90	-0.13	197.0	0.90	-0.10	0.83	-1.74	1.53
	Equal variances not assumed			-0.13	195.2	0.90	-0.10	0.83	-1.74	1.53
SEPTI TOTAL	Equal variances assumed	4.18	0.04	-0.94	197.0	0.35	-2.89	3.06	-8.92	3.15
	Equal variances not assumed			-0.95	193.1	0.34	-2.89	3.04	-8.88	3.10
Se-SLTR total	Equal variances assumed	0.44	0.51	-1.78	197.0	0.08	-2.05	1.16	-4.33	0.23
	Equal variances not assumed			-1.78	197.0	0.08	-2.05	1.15	-4.33	0.22
PETS credibility	Equal variances assumed	0.29	0.59	-0.89	197.0	0.38	-0.53	0.60	-1.70	0.65
	Equal variances not assumed			-0.88	192.7	0.38	-0.53	0.60	-1.71	0.65
PETS child improvement	Equal variances assumed	0.56	0.46	-0.53	197.0	0.60	-0.28	0.53	-1.32	0.76
	Equal variances not assumed			-0.53	195.8	0.60	-0.28	0.53	-1.32	0.76
PETS parents involvement	Equal variances assumed	0.00	0.95	-0.47	197.0	0.64	-0.11	0.25	-0.60	0.37
	Equal variances not assumed			-0.47	197.0	0.64	-0.11	0.24	-0.60	0.37
PETS Total	Equal variances assumed	0.10	0.75	-0.89	197.0	0.37	-1.00	1.12	-3.20	1.21
	Equal variances not assumed			-0.89	196.0	0.37	-1.00	1.12	-3.20	1.21
FOCUS Baseline	Equal variances assumed	0.53	0.47	-1.26	197.0	0.21	-10.31	8.15	-26.39	5.78
	Equal variances not assumed			-1.27	196.7	0.21	-10.31	8.12	-26.33	5.71

Appendix 8.6 Demographic Form

Participant Key Information Sheet

Participant Number																																																												
Child's name:																																																												
Ethnicity: (Please circle)	<table border="1"> <tr> <td colspan="2">WHITE</td> <td colspan="2">ASIAN OR ASIAN BRITISH</td> </tr> <tr> <td>British</td> <td>A</td> <td>Indian</td> <td>H</td> </tr> <tr> <td>Irish</td> <td>B</td> <td>Pakistani</td> <td>J</td> </tr> <tr> <td>Any other white background</td> <td>C</td> <td>Bangladeshi</td> <td>K</td> </tr> <tr> <td></td> <td></td> <td>Any other Asian background</td> <td>L</td> </tr> <tr> <td colspan="2">MIXED</td> <td colspan="2">BLACK OR BLACK BRITISH</td> </tr> <tr> <td>White and Black Caribbean</td> <td>D</td> <td>Caribbean</td> <td>M</td> </tr> <tr> <td>White and Black African</td> <td>E</td> <td>African</td> <td>N</td> </tr> <tr> <td>White and Asian</td> <td>F</td> <td>Any other black background</td> <td>P</td> </tr> <tr> <td>Any other mixed background</td> <td>G</td> <td></td> <td></td> </tr> <tr> <td></td> <td></td> <td colspan="2">OTHER ETHNIC GROUPS</td> </tr> <tr> <td></td> <td></td> <td>Chinese</td> <td>R</td> </tr> <tr> <td></td> <td></td> <td>Any other ethnic group</td> <td>S</td> </tr> <tr> <td></td> <td></td> <td>Not Stated</td> <td>Z</td> </tr> </table>				WHITE		ASIAN OR ASIAN BRITISH		British	A	Indian	H	Irish	B	Pakistani	J	Any other white background	C	Bangladeshi	K			Any other Asian background	L	MIXED		BLACK OR BLACK BRITISH		White and Black Caribbean	D	Caribbean	M	White and Black African	E	African	N	White and Asian	F	Any other black background	P	Any other mixed background	G					OTHER ETHNIC GROUPS				Chinese	R			Any other ethnic group	S			Not Stated	Z
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Mother's name: (who the child lives with, not necessarily biological)																																																												
Ethnicity: (Choose from above)																																																												
Marital Status:																																																												
Languages Spoken:																																																												
Father's name: (who the child lives with, not necessarily biological)																																																												
Ethnicity: (Choose from above)																																																												
Marital Status:																																																												

Household Composition

1. How many people live in your house? Can you tell me who each one is? (Use codes from below

Name	Age	Relationship to child	Code

17= Mother
18= Father
19= Adoptive mother
20= Adoptive father
21= Step-mother
22= Step-father
23= Mother's partner
24= Father's partner
25= Sister
26= Brother
27= Step-sister
28= Step-brother
29= Half-sister
30= Half-brother
31= Grandmother
32= Grandfather
If other please specify

Does one of the child's biological parents live at a different address as the child? If yes, state Mother/Father

2. How many brothers or sisters does your child have? How old are they? Are they biological siblings?

OBTAIN EDUCATIONAL AND WORK HISTORY FOR PARENTS RESIDING WITH PARTICIPANT

Parent 1 (Respondent)

1. What about your own education, where did you go to school? What kind of school was that?

2. How old were you when you left school?

3. Did you take any examinations?

Final educational qualification

0 = none

1 = 1-4 GCSE passes at GSE, GCSE, O level

2 = \geq 5 passes at GSE, GCSE, O level

3 = A levels or equivalent

4 = University

5 = Postgraduate degree

8 = N/A

9 = D/K

4. Did you do any further training or education after leaving school?

Work/professional training

0 = none

1 = on job training certificate (< 1mos)

2 = City & Guilds or equiv.

3 = Professional

4 = Apprenticeship

5 = Semi-professional

8 = N/A

9 = D/K

5. Are you working? **Yes** **No** **Past**

Job title _____

0= professionals: e.g. doctors, lawyers, teachers, managers

1= non-manual skilled: e.g. typist, police officer, fireman

2= manual skilled: e.g. toolmaker, foreman, ambulance man

3= partly skilled: e.g. bus conductor, postman

4= unskilled: cleaners, porters, messengers

5= chronically unemployed for the majority of adult life

6= homemaker who has not worked for majority of adult life

7= sheltered employment

8= still in full time education

9= not known

Parent 2

6. What about his/her other parent? Where did they go to school? What kind of school was that?

7. How old were they when they left school?

8. Did they take any examinations?

--	--

Final educational qualification

0 = none

1 = 1-4 GCSE passes at GSE, GCSE, O level

2 = \geq 5 passes at GSE, GCSE, O level

3 = A levels or equivalent

4 = University

5 = Postgraduate degree

8 = N/A

9 = D/K

9. Did they do any further training or education after leaving school?

--	--

Work/professional training

0 = none

1 = on job training certificate (< 1mos)

2 = City & Guilds or equiv.

3 = Professional

4 = Apprenticeship

5 = Semi-professional

8 = N/A

9 = D/K

10. Are they working? Yes No Past

--	--

Job title _____

0= professionals: e.g. doctors, lawyers, teachers, managers

1= non-manual skilled: e.g. typist, police officer, fireman

2= manual skilled: e.g. toolmaker, foreman, ambulance man

3= partly skilled: e.g. bus conductor, postman

4= unskilled: cleaners, porters, messengers

5= chronically unemployed for the majority of adult life

6= homemaker who has not worked for majority of adult life

7= sheltered employment

8= still in full time education

9= not known

Appendix 8.7 IPQR-SLCN

ILLNESS PERCEPTIONS QUESTIONNAIRE FOR SPEECH LANGUAGE COMMUNICATION NEEDS (IPQ-R SLCN)

Participant ID:

Date.....

Definitions:

Problem: means your child's speech language communication problem as a whole

Difficulties: means the different parts of your child's problems

YOUR VIEWS ABOUT YOUR CHILD'S COMMUNICATION PROBLEM

Listed below are a number of difficulties that your child may or may not have. Please indicate by circling Yes or No, whether your child has experienced any of these difficulties.

	POSSIBLE DIFFICULTIES YOUR CHILD MAY HAVE	My child has this difficulty		IF YES: This difficulty is related to my child's communication problem	
1	Repeats words or parts of words	Yes	No	Yes	No
2	Prolongs sounds e.g. ffffffffish	Yes	No	Yes	No
3	Doesn't speak clearly/is difficult to understand	Yes	No	Yes	No
4	Doesn't say speech sounds properly	Yes	No	Yes	No
5	Doesn't understand what is said to him/her e.g. doesn't follow instructions	Yes	No	Yes	No
6	Reduced vocabulary/has few words	Yes	No	Yes	No
7	Doesn't ask questions	Yes	No	Yes	No
8	Doesn't name objects	Yes	No	Yes	No
9	Doesn't put words together into sentences	Yes	No	Yes	No
10	Repeats what is said (when not asked to)	Yes	No	Yes	No
11	Has lost words he/she used to say	Yes	No	Yes	No
12	Doesn't use gestures	Yes	No	Yes	No
13	Is in his/her own world	Yes	No	Yes	No
14	Is over friendly e.g. will talk to complete strangers	Yes	No	Yes	No
15	Is shy	Yes	No	Yes	No
16	Has problems with eye contact	Yes	No	Yes	No
17	Doesn't share toys with other children	Yes	No	Yes	No
18	Dislikes being touched or held	Yes	No	Yes	No
19	Plays with objects repetitively or intensely	Yes	No	Yes	No
20	Rocks, flaps hands or makes other unusual movements	Yes	No	Yes	No
21	No fear of real dangers	Yes	No	Yes	No
22	Fussy eater	Yes	No	Yes	No
23	Sleep problems	Yes	No	Yes	No
24	Difficulties taking him/her on public transport	Yes	No	Yes	No
25	Is behind in his/her learning	Yes	No	Yes	No
26	Aggressive	Yes	No	Yes	No
27	Tantrums	Yes	No	Yes	No
28	Problems with attention/concentration	Yes	No	Yes	No
29	Impulsive, does things without thinking	Yes	No	Yes	No
30	Anxious/nervous/worried	Yes	No	Yes	No
31	Doesn't sit still	Yes	No	Yes	No

VIEWS ABOUT YOUR CHILD'S PROBLEM

I am interested in your own personal views of how you see your child's communication problem.

Please indicate how much you agree or disagree with the following statements about your child's problem by ticking the appropriate box.

Definitions: **Treatment** means **speech and language therapy intervention**.

	VIEWS ABOUT YOUR CHILD'S PROBLEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	My child's problem will last a short time					
IP2	My child's problem is likely to be permanent rather than temporary.					
IP3	My child's problem will last a long time					
IP4	My child's difficulties will pass quickly					
IP5	I expect my child to have this problem for the rest of their life.					
IP6	My child's problem is serious.					
IP7c	My child's problem has major consequences on their life					
IP7p	My child's problem has major consequences on my life					
IP8c	My child's problem does not have much effect on their life					
IP8p	My child's problem does not have much effect on my life					
IP9c	My child's problem strongly affects the way others see my child					
IP9p	My child's problem strongly affects the way others see me					
IP10	My child's problem has serious financial consequences.					
IP11	My child's problem causes difficulties for those who are close to my child					
IP12c	There is a lot my child can do to improve their difficulties					
IP12p	There is a lot I can do to improve my child's difficulties					
IP13c	What my child does can determine whether their problem gets better or worse.					
IP13p	What I do can determine whether my child's problem gets better or worse.					
IP14c	What happens with my child's problem depends on my child .					
IP14p	What happens with my child's problem depends on me .					
IP15c	Nothing my child does will affect their problem					
IP15p	Nothing I do will affect my child's problem					
IP16c	My child has the power to influence their problem					
IP16p	I have the power to influence my child's problem					
IP17c	My child's actions will have no effect on the outcome of their problem.					

	VIEWS ABOUT YOUR CHILD'S PROBLEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP17p	My actions will have no effect on the outcome of my child's problem.					
IP18	My child's problem will improve in time.					
IP19	There is little that can be done to improve my child's problem					
IP20	My child's treatment will be effective in curing my child's problem.					
IP21	The negative effects of my child's problem can be prevented (avoided) by my child's treatment.					
IP22	My child's treatment can control their problem					
IP23	There is nothing which can help my child's problem.					
IP24	My child's difficulties are puzzling to me					
IP25	My child's problem is a mystery to me.					
IP26	I don't understand my child's problem.					
IP27	My child's problem doesn't make any sense to me					
IP28	I have a clear picture or understanding of my child's problem.					
IP29	My child's difficulties change a great deal from day to day					
IP30	My child's difficulties come and go in cycles.					
IP31	My child's problem is very unpredictable					
IP32	My child goes through cycles in which his/her problem gets better and worse					
IP33	I get depressed when I think about my child's problem.					
IP34	When I think about my child's problem I get upset.					
IP35	My child's problem makes me feel angry					
IP36	My child's problem does not worry me					
IP37	My child having this problem makes me feel worried.					
IP38	My child's problem makes me fear for the future					

CAUSES OF MY CHILD'S COMMUNICATION PROBLEM

I am interested in what you think may have been the cause of your child's problem. As people are very different, there is no correct answer for this question. I am most interested in your own views about the things that caused your child's problem rather than what others including doctors, speech and language therapists or family may have suggested to you. Below is a list of possible causes for your child's problem. Please indicate how much you agree or disagree that they were a cause of your child's problem by ticking the appropriate box.

	MY CHILD'S PROBLEM IS CAUSED:	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	By hereditary reasons: it runs in mine or my partners side of the family					
C2	By my child's personality e.g. is shy					
C3	By my child's age					
C4	By my child's lack of experience with other children					
C5	By my child's emotional state					
C6	Because my child used a dummy(pacifier)/sucked their thumb					
C7	Because my child was born with it					
C8	Because my child started school too early					
C9	Because my child is developing in his/her own time					
C10	By my own behaviour e.g. I didn't do enough/the right things					
C11	By my emotional state e.g. feeling down, lonely, anxious, empty.					
C12	Because of family changes e.g. moving house, marital break-up, unhappy home.					
C13	Because the family speaks more than one language at home.					
C14	By problems during pregnancy.					
C15	Because my child was born prematurely					
C16	By my child being in hospital for a long time					
C17	Because of the tube my child had in his/her throat					
C18	By my child's surgery					
C19	Because of a problem with my child's brain and nerves					
C20	By my child's hearing problems					
C21	Because my child has a problem with his/her tongue					
C22	By being given vaccinations e.g. MMR					
C23	Because it is God's will.					
C24	By stress or worry					
C25	By a germ or virus					
C26	By diet or eating habits					
C27	By chance or bad luck					
C28	Because of pollution in the environment					
C29	Because of accident or injury					

In the table below, please list in the order of importance, the three most important things that you now believe caused YOUR CHILD'S problem. You may use any of the items from the box above, or you may have additional ideas of your own. The most important causes for me:

1. _____ 2. _____ 3. _____

Appendix 8.8 Sensitivity Analysis: Completers versus Drop-outs Post Interview 1

Independent Samples Test										
		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval	
									Lower	Upper
FLQ child comm	Equal variances assumed	1.06	0.30	-0.15	197.0	0.88	-0.07	0.48	-1.01	0.87
	Equal variances not assumed			-0.14	79.4	0.89	-0.07	0.50	-1.07	0.93
FLQ Family impact	Equal variances assumed	0.01	0.91	0.87	197.0	0.39	0.87	1.01	-1.11	2.86
	Equal variances not assumed			0.85	83.4	0.40	0.87	1.03	-1.17	2.92
FLQ confidence	Equal variances assumed	0.53	0.47	1.52	197.0	0.13	1.19	0.78	-0.35	2.72
	Equal variances not assumed			1.62	97.5	0.11	1.19	0.73	-0.27	2.64
FLQ child social	Equal variances assumed	1.47	0.23	0.46	197.0	0.64	0.35	0.76	-1.14	1.84
	Equal variances not assumed			0.43	76.9	0.67	0.35	0.81	-1.27	1.97
FLQ TX Experience	Equal variances assumed	0.14	0.71	-1.48	197.0	0.14	-0.72	0.49	-1.69	0.24
	Equal variances not assumed			-1.44	83.1	0.15	-0.72	0.50	-1.72	0.27
FLQTotal	Equal variances assumed	1.16	0.28	0.64	197.0	0.52	1.61	2.51	-3.33	6.56
	Equal variances not assumed			0.63	84.1	0.53	1.61	2.55	-3.46	6.69
ipqidsum	Equal variances assumed	0.16	0.69	0.32	197.0	0.75	0.25	0.80	-1.32	1.83
	Equal variances not assumed			0.31	83.7	0.76	0.25	0.82	-1.37	1.88
ipq_NOTRelated_to_SLCN_SUM	Equal variances assumed	0.40	0.53	1.48	197.0	0.14	0.74	0.50	-0.25	1.72
	Equal variances not assumed			1.54	94.1	0.13	0.74	0.48	-0.21	1.68
IPQR Timeline	Equal variances assumed	0.76	0.38	1.38	197.0	0.17	0.98	0.71	-0.42	2.38
	Equal variances not assumed			1.30	78.7	0.20	0.98	0.75	-0.52	2.48
IPQR Consequences	Equal variances assumed	5.00	0.03	1.09	197.0	0.28	1.27	1.16	-1.02	3.56
	Equal variances not assumed			1.01	76.2	0.32	1.27	1.26	-1.24	3.78

IPQR Conseq.Child	Equal variances assumed	0.05	0.83	1.50	197.0	0.14	0.71	0.47	-0.22	1.64
	Equal variances not assumed			1.48	84.4	0.14	0.71	0.48	-0.25	1.66
IPQR Conseq. Parent	Equal variances assumed	4.02	0.05	0.79	197.0	0.43	0.33	0.42	-0.50	1.16
	Equal variances not assumed			0.74	77.9	0.46	0.33	0.45	-0.56	1.23
IPQR Personal Control	Equal variances assumed	1.00	0.32	1.90	197.0	0.06	1.74	0.92	-0.07	3.55
	Equal variances not assumed			1.76	76.8	0.08	1.74	0.99	-0.23	3.71
IPQR Control Child	Equal variances assumed	3.87	0.05	3.74	197.0	0.00	2.31	0.62	1.09	3.53
	Equal variances not assumed			3.24	69.8	0.00	2.31	0.71	0.89	3.73
IPQR Control Parent	Equal variances assumed	0.14	0.71	-0.84	197.0	0.40	-0.57	0.68	-1.91	0.77
	Equal variances not assumed			-0.82	83.9	0.41	-0.57	0.70	-1.95	0.81
IPQR Treatment Control	Equal variances assumed	0.01	0.92	0.09	197.0	0.93	0.04	0.42	-0.78	0.86
	Equal variances not assumed			0.09	81.6	0.93	0.04	0.43	-0.82	0.90
IPQR Coherence	Equal variances assumed	0.53	0.47	-0.06	197.0	0.95	-0.04	0.60	-1.22	1.14
	Equal variances not assumed			-0.06	80.6	0.95	-0.04	0.63	-1.28	1.21
IPQR Timeline Cyclical	Equal variances assumed	5.43	0.02	-1.79	197.0	0.08	-0.97	0.54	-2.05	0.10
	Equal variances not assumed			-1.64	75.7	0.11	-0.97	0.59	-2.16	0.21
IPQR Emot. representations	Equal variances assumed	0.01	0.94	0.02	197.0	0.99	0.01	0.82	-1.60	1.63
	Equal variances not assumed			0.02	85.3	0.99	0.01	0.83	-1.63	1.66
SEPTI Emot.avail	Equal variances assumed	0.03	0.86	-1.82	197.0	0.07	-1.17	0.64	-2.43	0.10
	Equal variances not assumed			-1.84	88.2	0.07	-1.17	0.63	-2.43	0.10
SEPTI Nurture	Equal variances assumed	0.37	0.54	-0.67	197.0	0.50	-0.38	0.57	-1.50	0.74
	Equal variances not assumed			-0.69	91.6	0.49	-0.38	0.55	-1.48	0.71
SEPTI Discipline	Equal variances assumed	0.06	0.80	-0.45	197.0	0.66	-0.34	0.75	-1.82	1.15
	Equal variances not assumed			-0.44	85.6	0.66	-0.34	0.76	-1.85	1.18
SEPTI Play	Equal variances assumed	0.54	0.46	-0.96	197.0	0.34	-0.79	0.83	-2.42	0.84
	Equal variances not assumed			-1.04	100.9	0.30	-0.79	0.76	-2.31	0.72
SEPTI Teach	Equal variances assumed	1.00	0.32	0.03	197.0	0.98	0.03	0.98	-1.91	1.97
	Equal variances not assumed			0.03	101.4	0.98	0.03	0.91	-1.77	1.83

SEPTI Icare	Equal variances assumed	1.00	0.32	-0.14	197.0	0.89	-0.13	0.95	-2.00	1.74
	Equal variances not assumed			-0.15	106.6	0.88	-0.13	0.86	-1.83	1.57
SEPTI TOTAL	Equal variances assumed	2.99	0.09	-0.79	197.0	0.43	-2.78	3.50	-9.69	4.13
	Equal variances not assumed			-0.89	110.0	0.37	-2.78	3.12	-8.95	3.40
Se-SLTR total	Equal variances assumed	0.03	0.86	-0.48	197.0	0.63	-0.64	1.33	-3.27	1.98
	Equal variances not assumed			-0.49	89.4	0.62	-0.64	1.31	-3.25	1.96
PETS credibility	Equal variances assumed	0.01	0.94	2.09	197.0	0.04	1.41	0.68	0.08	2.75
	Equal variances not assumed			1.96	78.0	0.05	1.41	0.72	-0.02	2.85
PETS child improvement	Equal variances assumed	0.39	0.53	-0.44	197.0	0.66	-0.27	0.61	-1.46	0.93
	Equal variances not assumed			-0.44	86.4	0.66	-0.27	0.61	-1.48	0.94
PETS parents involvement	Equal variances assumed	0.05	0.82	1.36	197.0	0.17	0.52	0.38	-0.23	1.28
	Equal variances not assumed			1.34	84.5	0.18	0.52	0.39	-0.25	1.30
PETS Total	Equal variances assumed	0.26	0.61	1.26	197.0	0.21	1.67	1.33	-0.95	4.29
	Equal variances not assumed			1.21	82.1	0.23	1.67	1.37	-1.06	4.40
FOCUS Baseline	Equal variances assumed	0.86	0.36	-1.16	197.0	0.25	-10.8	9.34	-29.2	7.60
	Equal variances not assumed			-1.13	83.6	0.26	-10.8	9.55	-29.8	8.17
Maternal age	Equal variances assumed	0.94	0.33	-0.90	191.0	0.37	-0.88	0.97	-2.80	1.04
	Equal variances not assumed			-0.95	91.4	0.35	-0.88	0.92	-2.71	0.96
Deprivation score	Equal variances assumed	0.00	0.97	1.35	244.0	0.18	1.78	1.31	-0.81	4.37
	Equal variances not assumed			1.36	81.2	0.18	1.78	1.30	-0.82	4.38

APPENDICES FOR CHAPTER NINE

Appendix 9.1 Non-significant Correlations with DNA

Appendix 9.2 Non-significant Correlations with Dadh

Appendix 9.3 Non-significant Correlations with Child Outcome

Appendix 9.1 Non-significant Correlations with DNA

1. Parent Beliefs IPQRSLCN - Non-significant Correlations with DNA (Spearman's rho)

		DNA	Timeline	Consequences	Conseq Child	Conseq Parent	Personal Control	Control Child	Control Parent	Treatment Control	Coherence	Emotional reps	child-related	number-cause
DNA	Correlation	1.00												
	Sig. (2-tailed)													
Timeline	Correlation	.04	1.00											
	Sig. (2-tailed)	.57												
Consequences	Correlation	.09	.54**	1.00										
	Sig. (2-tailed)	.21	.00											
Conseq Child	Correlation	.02	.45**	.90**	1.00									
	Sig. (2-tailed)	.77	.00	.00										
Conseq. Parent	Correlation	.12	.46**	.93**	.80**	1.00								
	Sig. (2-tailed)	.09	.00	.00	.00									
Personal Control	Correlation	-.13	.00	.07	.15*	.07	1.00							
	Sig. (2-tailed)	.07	.96	.32	.03	.30								
Control Child	Correlation	-.07	.12	.02	-.03	.01	.62**	1.00						
	Sig. (2-tailed)	.35	.08	.73	.68	.93	.00							
Control Parent	Correlation	-.10	-.12	.08	.23**	.09	.72**	-.04	1.00					
	Sig. (2-tailed)	.17	.09	.27	.00	.18	.00	.60						
Treatment Control	Correlation	-.10	-.33**	-.18*	-.08	-.16*	.32**	.02	.39**	1.00				
	Sig. (2-tailed)	.18	.00	.01	.25	.02	.00	.76	.00					
Coherence	Correlation	-.03	-.33**	-.33**	-.28**	-.31**	.16*	.10	.16*	.32**	1.00			
	Sig. (2-tailed)	.68	.00	.00	.00	.00	.02	.16	.03	.00				
Emotional reps	Correlation	.05	.45**	.65**	.57**	.60**	.07	.08	.02	-.20**	-.37**	1.00		
	Sig. (2-tailed)	.48	.00	.00	.00	.00	.36	.25	.81	.00	.00			
child-related	Correlation	.05	.00	.10	.02	.08	-.08	.07	-.17*	-.15*	-.23**	.27**	1.00	
	Sig. (2-tailed)	.46	.98	.15	.74	.24	.29	.30	.01	.04	.00	.00		
number-cause	Correlation	.09	.09	.163*	.08	.151*	-.05	.12	-.15*	-.09	-.24**	.32**	.46**	1.00
	Sig. (2-tailed)	.22	.22	.02	.25	.03	.52	.09	.03	.23	.00	.00	.00	

** . Correlation is significant at the 0.01 level (2-tailed).

2.Parent Self-Efficacy: Non-significant Correlations with DNA (Spearman's rho)

		DNA	FLQ confidence	SEPTI Emot. Avail	SEPTI Nurture	SEPTI Discipline	SEPTI play	SEPTI total	se-sltr
DNA	Correlation	1.00							
	Sig. (2-tailed)								
FLQ confidence	Correlation	-.10	1.00						
	Sig. (2-tailed)	.17							
SEPTI Emot. Avail	Correlation	.03	-.40**	1.00					
	Sig. (2-tailed)	.72	.00						
SEPTI Nurture	Correlation	-.06	-.24**	.67**	1.00				
	Sig. (2-tailed)	.42	.00	.00					
SEPTI Discipline	Correlation	-.08	-.45**	.43**	.38**	1.00			
	Sig. (2-tailed)	.25	.00	.00	.00				
SEPTI play	Correlation	-.02	-.28**	.48**	.55**	.40**	1.00		
	Sig. (2-tailed)	.73	.00	.00	.00	.00			
SEPTI total	Correlation	-.12	-.39**	.73**	.70**	.73**	.67**	1.00	
	Sig. (2-tailed)	.08	.00	.00	.00	.00	.00		
se-sltr	Correlation	-.01	-.28**	.38**	.23**	.26**	.25**	.37**	1.00
	Sig. (2-tailed)	.85	.00	.00	.00	.00	.00	.00	

** . Correlation is significant at the 0.01 level (2-tailed).

3.Child Characteristics: Non-significant Correlations with DNA (Spearman's rho)

		dna	IPQR Id Language	IPQR Id other	FLQ child comm	FLQ child social	FOCUS Baseline
dna	Correlation	1.00					
	Sig. (2-tailed)						
IPQR Id Language	Correlation	.07	1.00				
	Sig. (2-tailed)	.35					
IPQR Id other	Correlation	.09	.22**	1.00			
	Sig. (2-tailed)	.21	.00				
FLQ child comm	Correlation	.09	.44**	.15*	1.00		
	Sig. (2-tailed)	.19	.00	.03			
FLQ child social	Correlation	.10	.35**	.21**	.72**	1.00	
	Sig. (2-tailed)	.18	.00	.00	.00		
FOCUS Baseline	Correlation	-.09	-.64**	-.28**	-.70**	-.71**	1.00
	Sig. (2-tailed)	.19	.00	.00	.00	.00	

** . Correlation is significant at the 0.01 level (2-tailed).

4.Treatment Experience Baseline: Non-significant Correlations with DNA (Spearman's rho)

		dna	FLQ Treatment Exp	IPQR Treatment Control	PETS credibility	PETS child improvement	PETS parents involv	PETS total
dna	Correlation	1.00						
	Sig. (2-tailed)							
FLQ Treatment Exp	Correlation	.12	1.00					
	Sig. (2-tailed)	.09						
IPQR Treatment Control	Correlation	-.10	-.24**	1.00				
	Sig. (2-tailed)	.18	.00					
PETS credibility	Correlation	.00	-.31**	.39**	1.00			
	Sig. (2-tailed)	.99	.00	.00				
PETS child improvement	Correlation	-.01	-.33**	.42**	.61**	1.00		
	Sig. (2-tailed)	.90	.00	.00	.00			
PETS parents involv	Correlation	-.03	-.26**	.38**	.51**	.75**	1.00	
	Sig. (2-tailed)	.63	.00	.00	.00	.00		
PETS total	Correlation	-.03	-.34**	.42**	.88**	.85**	.73**	1.00
	Sig. (2-tailed)	.72	.00	.00	.00	.00	.00	

** . Correlation is significant at the 0.01 level (2-tailed).

5.Treatment Experience Follow-up: Non-significant Correlations with DNA (Spearman's rho) significance** . .01 level * . .05 level

		DNA	IPQR Treat. Control	WAI Total	Rec importance	BTPS Relevance	BTPS Relations SLT	BTPS Treat. issues	BTPS Total Barriers	CSPQ 1stExp	CSPQ Satisfaction	CSPQ Parent role	CSPQ SLT helpful	CSPQ Total
DNA	Correlation	1.00												
	Sig. (2-tailed)													
IPQR Treatment Control	Correlation	-.15	1.00											
	Sig. (2-tailed)	.07												
WAI Total	Correlation	-.11	.31**	1.00										
	Sig. (2-tailed)	.18	.00											
Degree of rec importance	Correlation	-.04	.32**	.40**	1.00									
	Sig. (2-tailed)	.67	.00	.00										
BTPS Relevance	Correlation	.07	-.31**	-.51**	-.36**	1.00								
	Sig. (2-tailed)	.40	.00	.00	.00									
BTPS Relationship SLT	Correlation	-.09	-.22**	-.30**	-.12	.44**	1.00							
	Sig. (2-tailed)	.29	.01	.00	.16	.00								
BTPS Treatment issues	Correlation	.02	-.15	-.43**	-.31**	.57**	.47**	1.00						
	Sig. (2-tailed)	.81	.06	.00	.00	.00	.00							
BTPS Total Barriers	Correlation	.13	-.17	-.49**	-.37**	.68**	.50**	.70**	1.00					
	Sig. (2-tailed)	.11	.04	.00	.00	.00	.00	.00						
CSPQ 1stExp	Correlation	-.10	.25**	.54**	.34**	-.38**	-.24**	-.36**	-.40**	1.00				
	Sig. (2-tailed)	.24	.00	.00	.00	.00	.00	.00	.00					
CSPQ Satisfaction	Correlation	-.06	.30**	.67**	.40**	-.47**	-.30**	-.40**	-.37**	.58**	1.00			
	Sig. (2-tailed)	.51	.00	.00	.00	.00	.00	.00	.00	.00				
CSPQ Parent role	Correlation	-.10	.15	.27**	.26**	-.09	-.13	-.10	-.10	.49**	.41**	1.00		
	Sig. (2-tailed)	.21	.07	.00	.00	.25	.10	.21	.22	.00	.00			
CSPQ SLT helpful	Correlation	-.09	.13	.56**	.38**	-.36**	-.25**	-.34**	-.33**	.58**	.72**	.54**	1.00	
	Sig. (2-tailed)	.30	.10	.00	.00	.00	.00	.00	.00	.00	.00	.00		
CSPQ Total	Correlation	-.08	.26**	.65**	.44**	-.43**	-.29**	-.39**	-.38**	.78**	.89**	.66**	.87**	1.00
	Sig. (2-tailed)	.33	.00	.00	.00	.00	.00	.00	.00	.00	.00	.00	.00	

Appendix 9.2 Non-significant Correlations with Dadh

1. Personal Circumstance: Non-significant Correlations with DNA (Spearman's rho)						
		Dadh	Child Age	Deprivation score	maternal age	Maternal education
Dadh	Correlation Coefficient	1.00				
	Sig. (2- tailed)					
Child age	Correlation Coefficient	.01	1.00			
	Sig. (2- tailed)	.92				
Deprivation score	Correlation Coefficient	.07	.01	1.00		
	Sig. (2- tailed)	.38	.85			
maternal age	Correlation Coefficient	-.04	.01	-.16*	1.00	
	Sig. (2- tailed)	.64	.93	.02		
Maternal education	Correlation Coefficient	-.13	-.07	-.34**	.19**	1.00
	Sig. (2- tailed)	.13	.31	.00	.01	

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

2.Parent Beliefs IPQRSLCN - Non-significant Correlations with DNA (Spearman's rho) significance**, .01 level *, .05 level

	Dadh	IPQR Timeline	IPQR Consequences	IPQR Personal Control	IPQR Control Child	IPQR Control Parent	IPQR Treatment	IPQR Coherence	IPQR Timeline Cyclical	IPQR external cause	IPQR early medical cause	IPQR child related cause	Total number causes
Dadh Correlation	1.00												
Sig. (2-tailed)													
IPQR Timeline Correlation	-.15	1.00											
Sig. (2-tailed)	.06												
IPQR Consequences Correlation	-.13	.46**	1.00										
Sig. (2-tailed)	.13	.00											
IPQR Personal Control Correlation	.00	.00	.07	1.00									
Sig. (2-tailed)	.97	.96	.30										
IPQR Control Child Correlation	-.03	.12	.01	.62**	1.00								
Sig. (2-tailed)	.76	.08	.93	.00									
IPQR Control Parent Correlation	-.02	-.12	.09	.72**	-.04	1.00							
Sig. (2-tailed)	.79	.09	.18	.00	.60								
IPQR Treatment Correlation	.11	-.33**	-.16*	.32**	.02	.39**	1.00						
Sig. (2-tailed)	.17	.00	.02	.00	.76	.00							
IPQR Coherence Correlation	.14	-.33**	-.31**	.16*	.10	.16*	.32**	1.00					
Sig. (2-tailed)	.08	.00	.00	.02	.16	.03	.00						
IPQR Timeline Cyclical Correlation	-.07	.30**	.45**	-.06	-.07	-.05	-.22**	-.32**	1.00				
Sig. (2-tailed)	.37	.00	.00	.38	.32	.53	.00	.00					
IPQR external cause Correlation	.10	.09	.21**	-.20**	.00	-.22**	-.19**	-.23**	.30**	1.00			
Sig. (2-tailed)	.21	.23	.00	.00	.97	.00	.01	.00	.00				
IPQR early medical cause Correlation	.05	.04	.20**	-.18**	-.07	-.14	-.15*	-.10	.19**	.48**	1.00		
Sig. (2-tailed)	.55	.56	.01	.01	.32	.05	.04	.15	.01	.00			
IPQR child related cause Correlation	.01	.00	.08	-.08	.07	-.17*	-.15*	-.23**	.27**	.24**	.15*	1.00	
Sig. (2-tailed)	.89	.98	.24	.29	.30	.01	.04	.00	.00	.00	.04		
Total number causes Correlation	-.05	.09	.15*	-.05	.12	-.15*	-.09	-.24**	.17*	.40**	.25**	.46*	1.00
Sig. (2-tailed)	.56	.22	.03	.52	.09	.03	.23	.00	.02	.00	.00	.00	

Appendix 9.3 Non-significant Correlations with Child Outcome

1. Personal Circumstances Non-significant Correlations with Child Outcome					
		FOCUS Follow-up	Deprivation score	Maternal Age	Maternal Education
FOCUS Follow-up	Pearson Correlation	1.00			
	Sig. (2-tailed)				
Deprivation score	Pearson Correlation	-.13	1.00		
	Sig. (2-tailed)	.12			
Maternal Age	Pearson Correlation	.16	-.19**	1.00	
	Sig. (2-tailed)	.05	.01		
Maternal Education	Pearson Correlation	.04	-.35**	.19**	1.00
	Sig. (2-tailed)	.64	.00	0.01	

** . Correlation is significant at the 0.01 level (2-tailed).

2. Parent Beliefs Non-significant Correlations with Child Outcome							
		FOCUS Follow-up	IPQR Personal	IPQR Control Child	IPQR Control Parent	IPQR external cause	IPQR child related cause
FOCUS Follow-up	Pearson Correlation Sig. (2-tailed)	1.00					
IPQR Personal Control	Pearson Correlation Sig. (2-tailed)	.12 .14	1.00				
IPQR Control Child	Pearson Correlation Sig. (2-tailed)	.02 .84	.68** .00	1.00			
IPQR Control Parent	Pearson Correlation Sig. (2-tailed)	.14 .08	.72** .00	-.02 .79	1.00		
IPQR external cause	Pearson Correlation Sig. (2-tailed)	-.08 .34	-.17* .01	.00 .98	-.23** .00	1.00	
IPQR child related cause	Pearson Correlation Sig. (2-tailed)	-.13 .12	-.08 .28	.05 .45	-.16* .03	.24** .00	1.00

** . Correlation is significant at the 0.01 level (2-tailed). * . Correlation is significant at the 0.05 level (2-tailed).

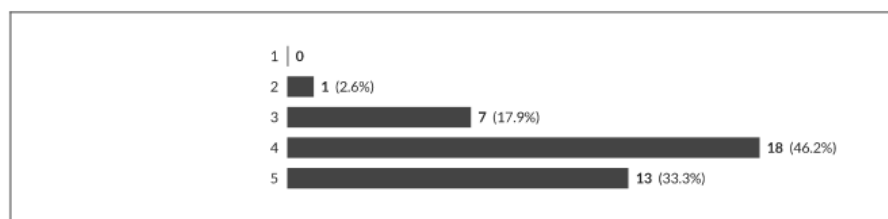
2. Parent Beliefs Non-significant Correlations with Child Outcome ** significant 0.01 level.					
	SPEARMANS Rho	FOCUS Follow-up	IPQR selfblame cause	IPQR early medical cause	IPQR number causes
FOCUS Follow-up	Correlation	1.00			
	Sig. (2-tailed)				
IPQR selfblame cause	Correlation	-.10	1.00		
	Sig. (2-tailed)	.25			
IPQR early medical cause	Correlation	-.08	.26**	1.00	
	Sig. (2-tailed)	.32	.00		
IPQR number causes	Correlation	-.05	.46**	.25**	1.00
	Sig. (2-tailed)	.52	.00	.00	

3. Parent Self-efficacy Non-significant Correlations with Child Outcome			
	SPEARMANS Rho	FOCUS Follow-up	SE-SLTR total
FOCUS Follow-up	Correlation	1.00	
	Sig. (2-tailed)		
SE-SLTR total	Correlation	.09	1.00
	Sig. (2-tailed)	.26	

APPENDICES FOR CHAPTER TEN

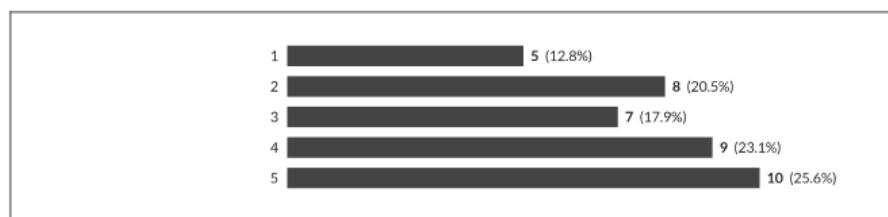
Appendix 10.1 Survey of SLTherapists

Appendix 10.1 Survey of SLTherapists



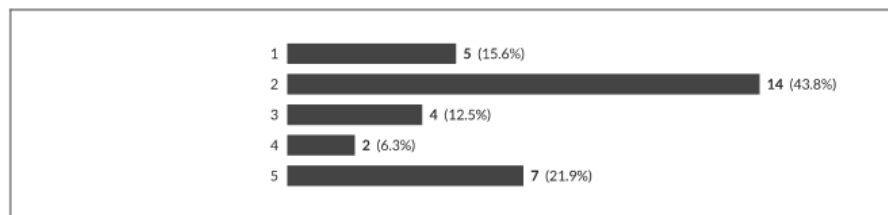
4 I knew where all the details on the study were saved on Comshare

4.1 Strongly disagree vs Strongly agree



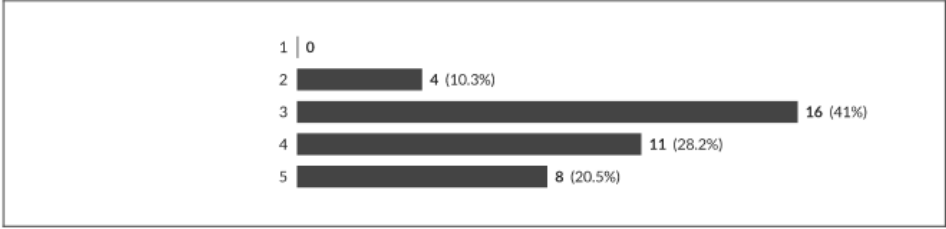
5 I was asked to provide descriptions of parents responses to therapy

5.1 Strongly disagree vs Strongly agree



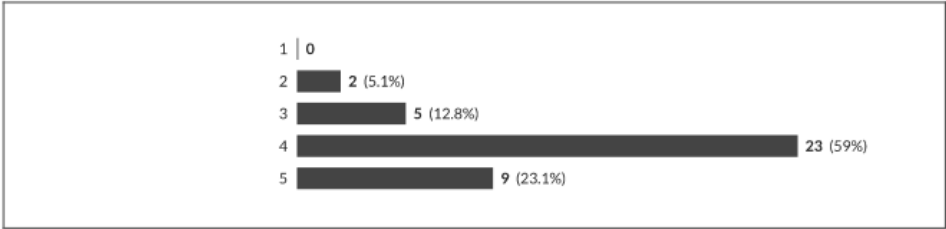
6 I love being actively involved in research

6.1 Strongly disagree vs Strongly agree



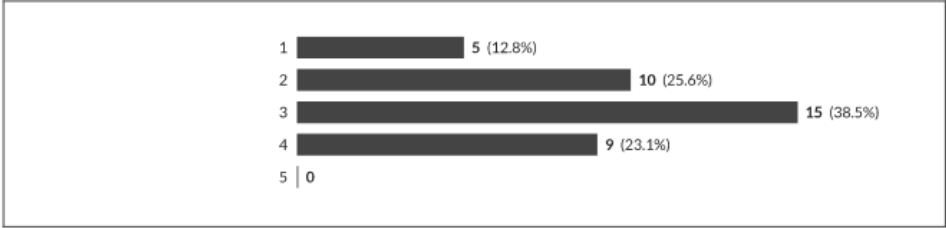
7 The speech therapy department values all research activity.

7.1 Strongly disagree vs Strongly agree



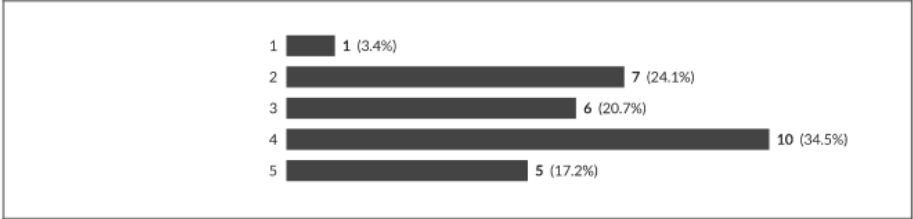
8 The research was about me and other speech and language therapists

8.1 Strongly disagree vs Strongly agree



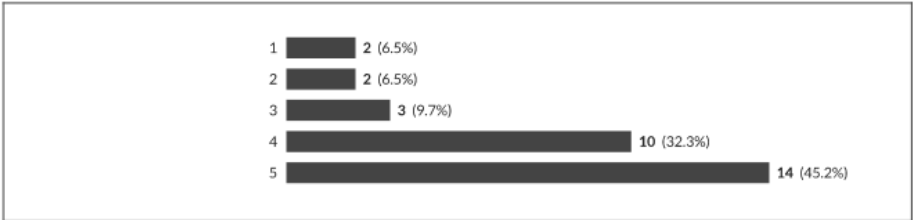
9 I was supported by my cluster lead/line manager in participating in this research

9.1 Strongly disagree vs Strongly agree



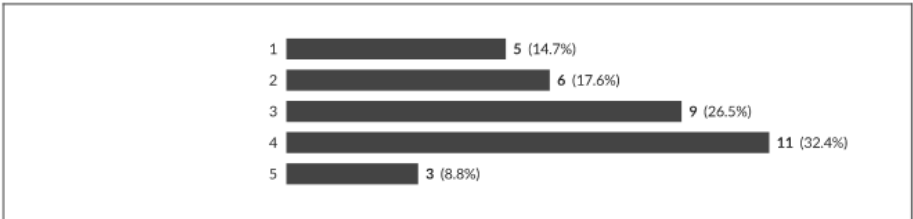
10 I had the opportunity to meet with the researcher directly either in 1:1 or groups

10.1 Strongly disagree vs Strongly agree



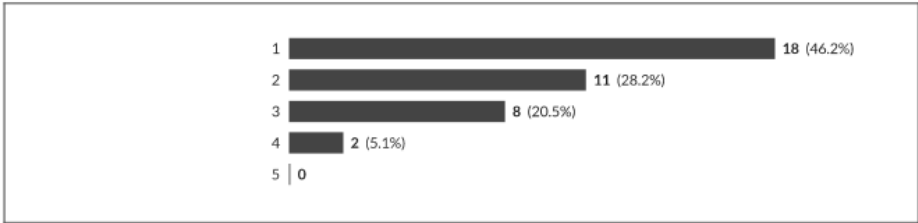
11 I felt bombarded by emails

11.1 Strongly disagree vs Strongly agree



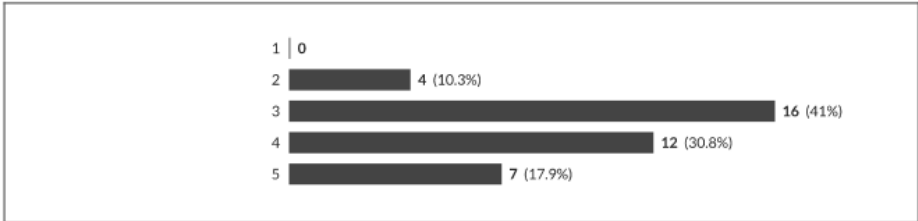
12 Research is not my job

12.1 Strongly disagree vs Strongly agree



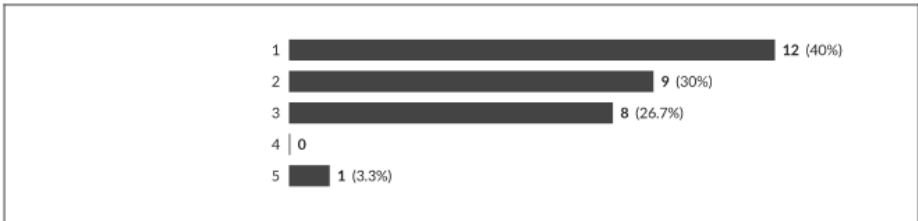
13 The study was qualitative

13.1 Strongly disagree vs Strongly agree



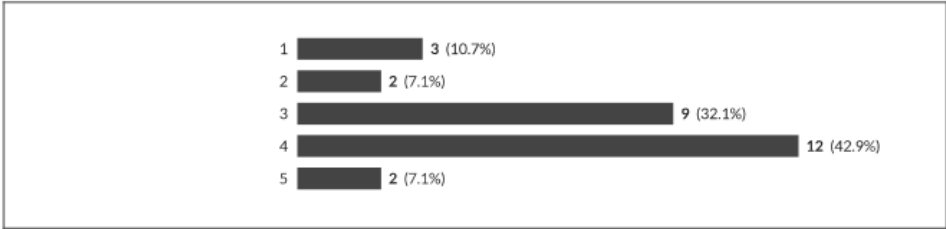
14 I was asked to provide reasons for parents not turning up to an appointment

14.1 Strongly disagree vs Strongly agree



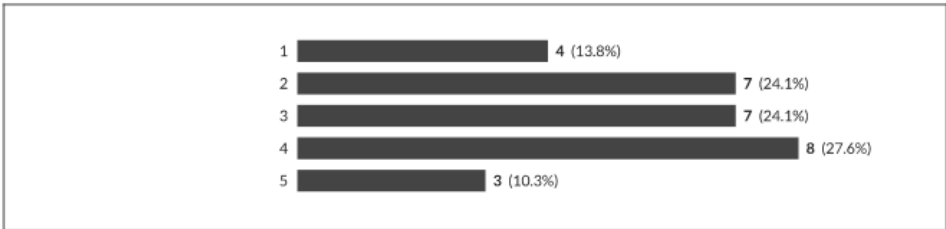
15 I was asked to ensure that when children changed therapist it was the responsibility of the new therapist to collate the study information

15.1 Strongly disagree vs Strongly agree



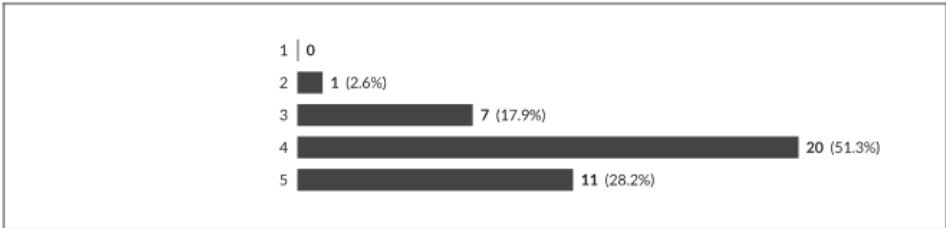
16 I had to record on RiO that a child was participating in research

16.1 Strongly disagree vs Strongly agree



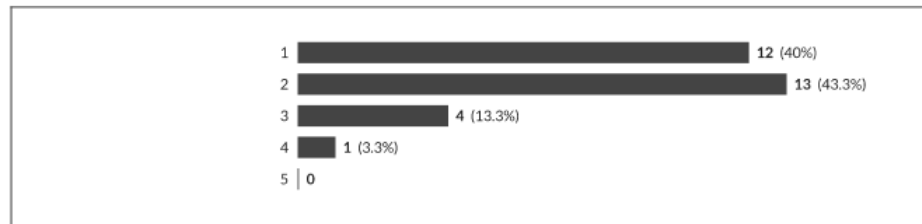
17 Research is highly important to me personally

17.1 Strongly disagree vs Strongly agree



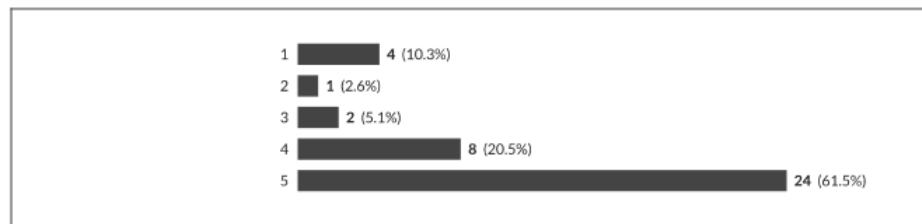
18 I did not see why I had to do this extra work.

18.1 Strongly disagree vs Strongly agree



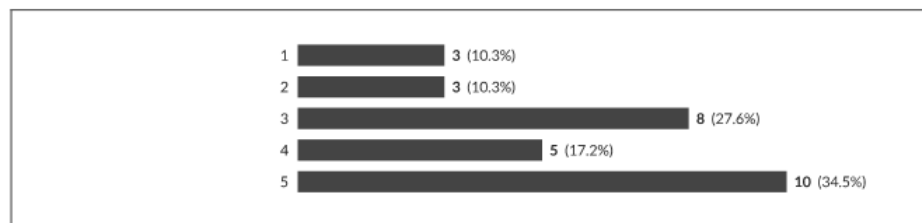
19 I attended a department presentation on the research

19.1 Strongly disagree vs Strongly agree



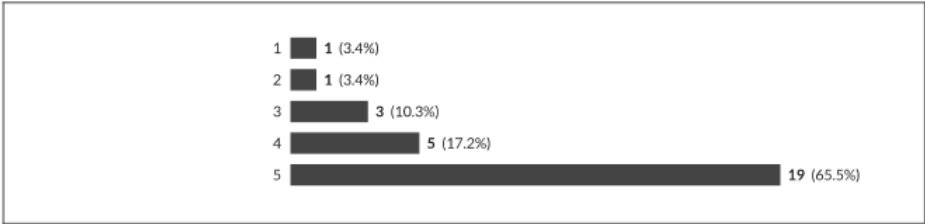
20 I was asked to check that there were no safeguarding concerns after obtaining consent for the researcher to contact the parents

20.1 Strongly disagree vs Strongly agree



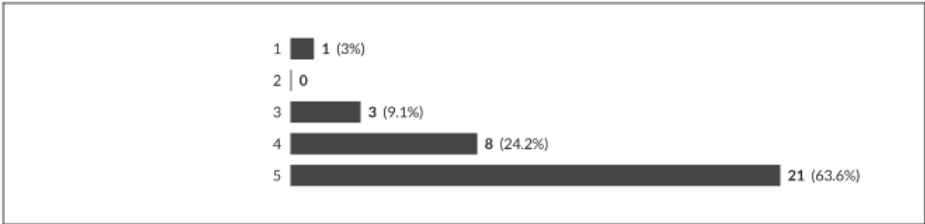
21 I had to carry out a DEAP/PLS or Lidcombe rating scale depending on child presentation

21.1 Strongly disagree vs Strongly agree



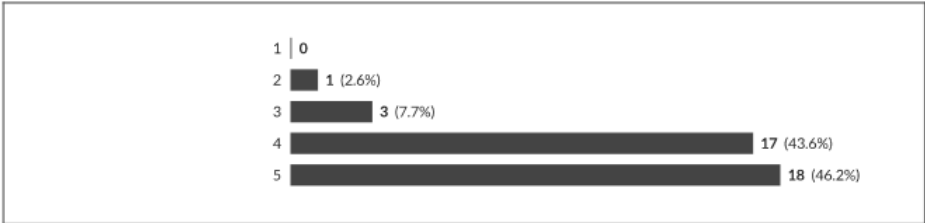
22 Parents were interviewed on two separate occasions

22.1 Strongly disagree vs Strongly agree



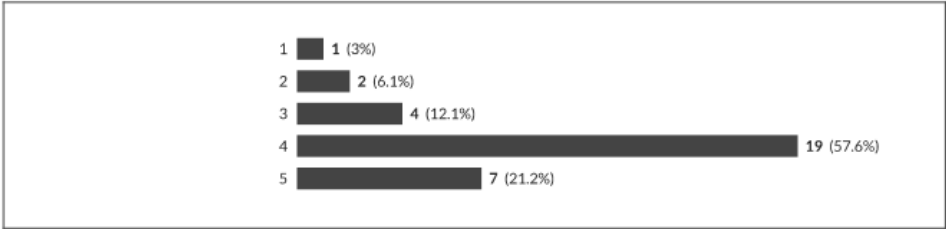
23 The findings of this study have strong practical applications to any community SLT service

23.1 Strongly disagree vs Strongly agree



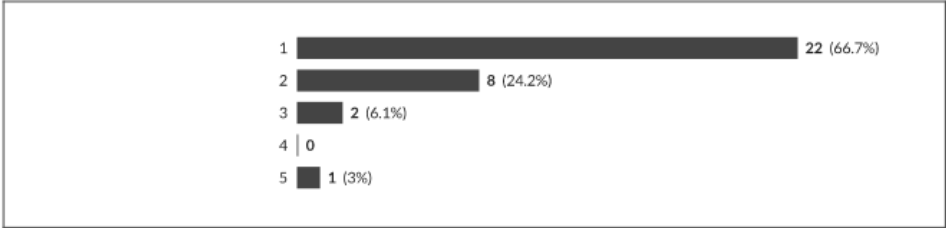
24 I understood exactly what was expected of me during the research study

24.1 Strongly disagree vs Strongly agree



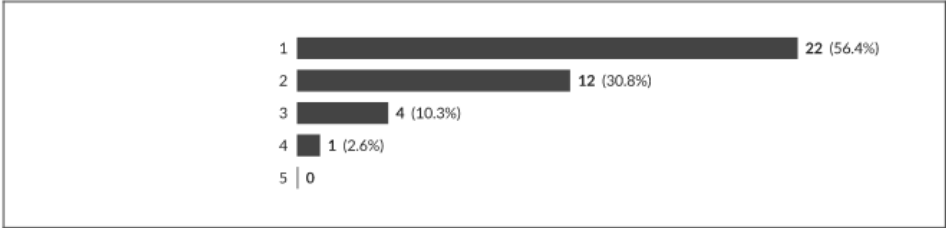
25 The study involved interviewing parents once

25.1 Strongly disagree vs Strongly agree



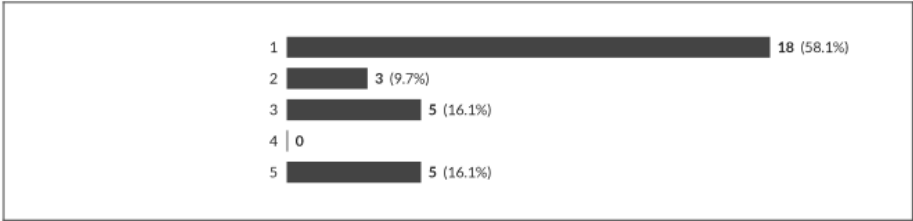
26 The study related to autism spectrum disorders

26.1 Strongly disagree vs Strongly agree



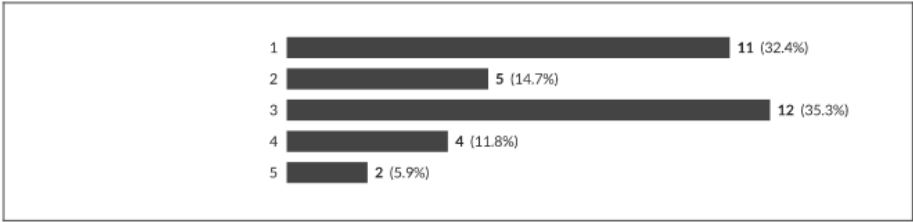
27 I was asked to invite all parents regardless of language spoken at home

27.1 Strongly disagree vs Strongly agree



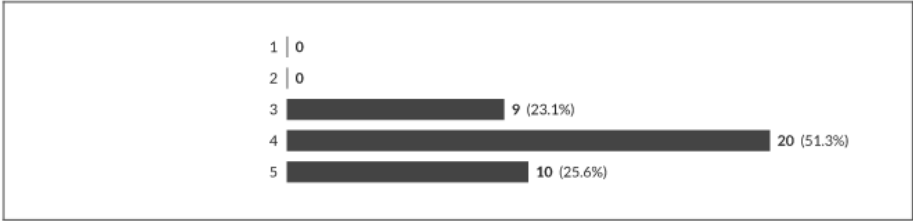
28 The main study was quantitative

28.1 Strongly disagree vs Strongly agree



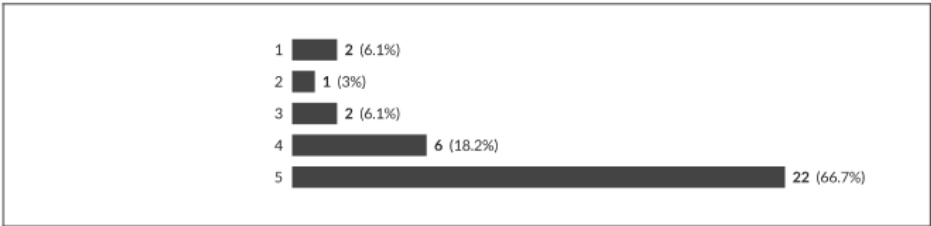
29 Therapists should do more research as a part of their clinical role.

29.1 Strongly disagree vs Strongly agree



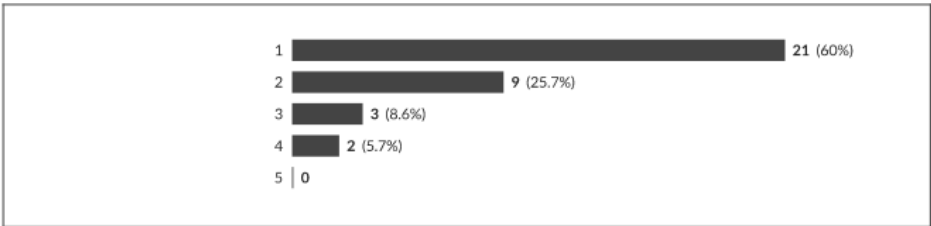
30 I was asked to set GAS targets for all children

30.1 Strongly disagree vs Strongly agree



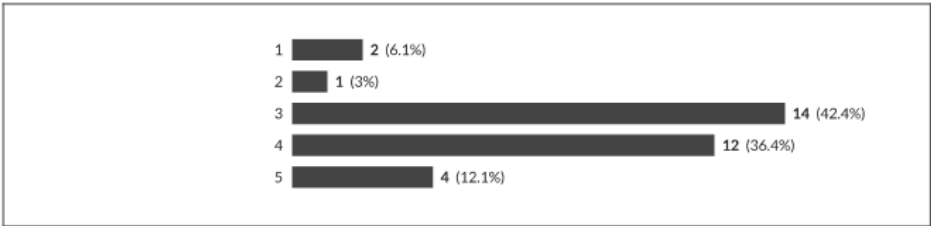
31 Penny assessed the children individually

31.1 Strongly disagree vs Strongly agree



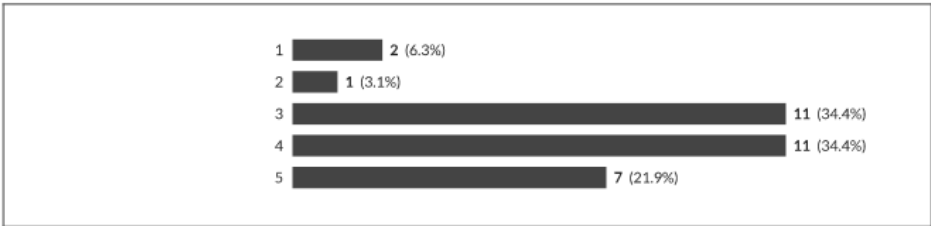
32 I felt confident in my ability to contribute to the research.

32.1 Strongly disagree vs Strongly agree



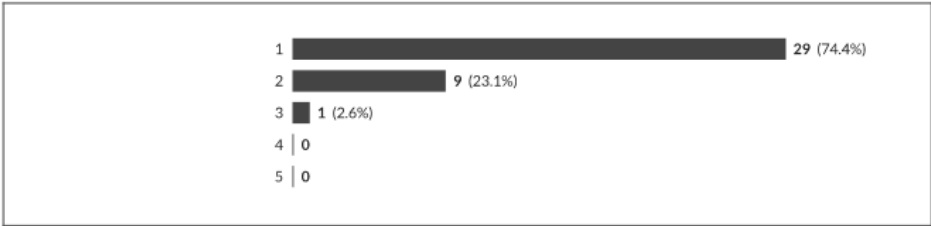
33 I knew there was a database of all the included research participants

33.1 Strongly disagree vs Strongly agree



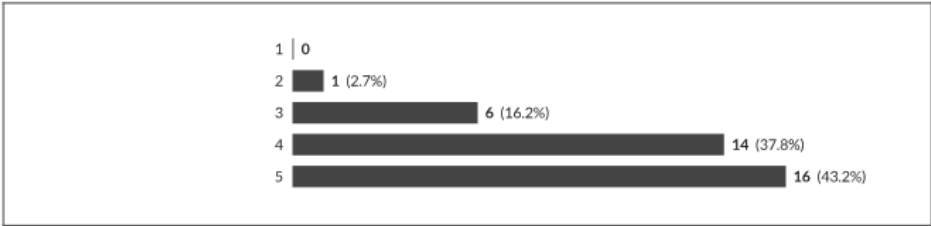
34 The research is not really relevant to the speech therapy profession

34.1 Strongly disagree vs Strongly agree



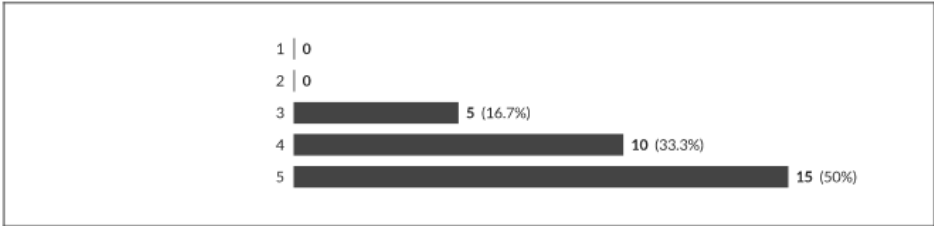
35 Department presentations on the research were interesting

35.1 Strongly disagree vs Strongly agree



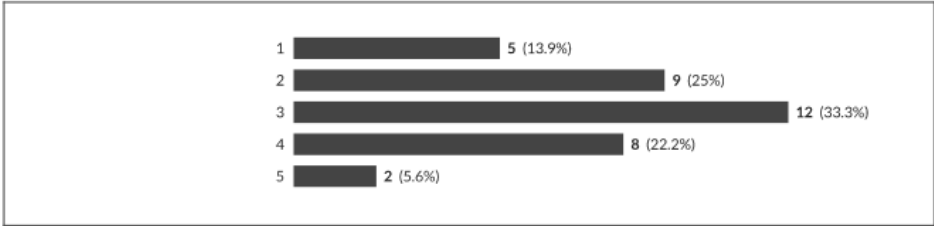
36 I was asked to identify that a child was participating in the research on the cluster database

36.1 Strongly disagree vs Strongly agree



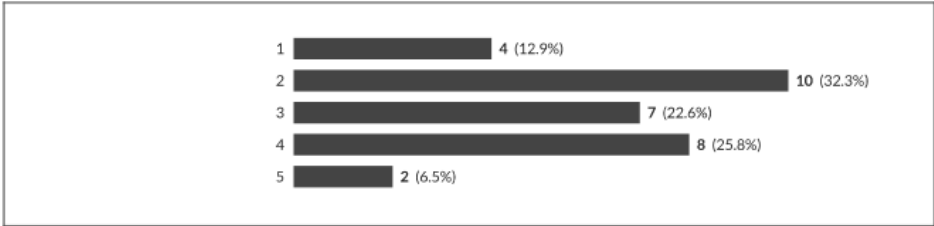
37 This study was about predicting who attends appointments

37.1 Strongly disagree vs Strongly agree



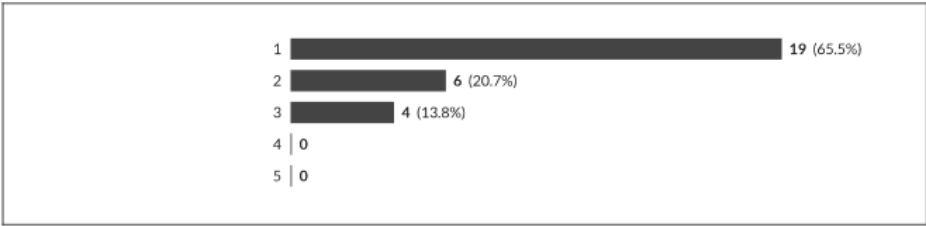
38 I had enough time to provide the information that Penny asked for

38.1 Strongly disagree vs Strongly agree



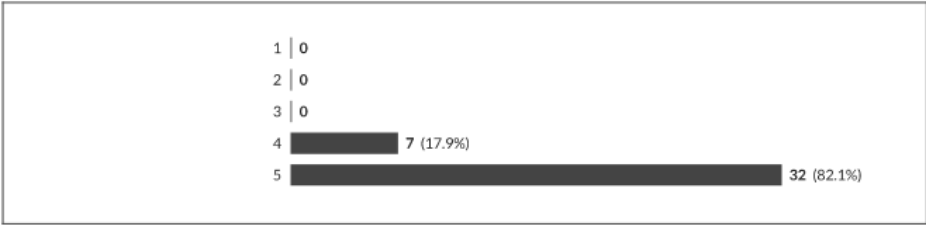
39 I was asked to carry out the PLS on all children in the study

39.1 Strongly disagree vs Strongly agree



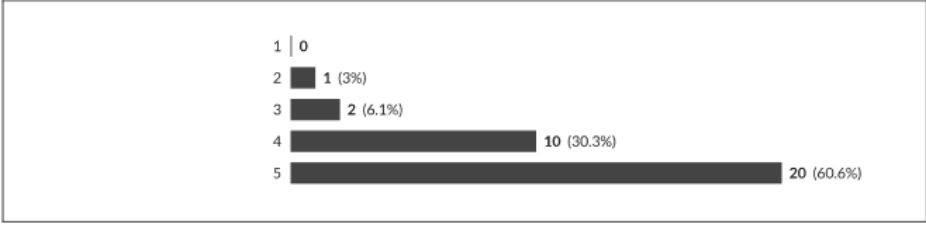
40 Research is important for the profession

40.1 Strongly disagree vs Strongly agree



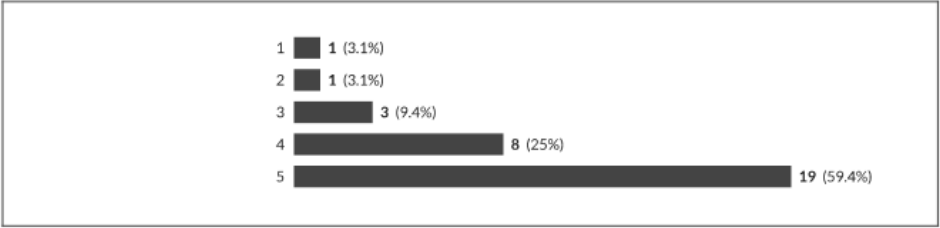
41 I read the SLT information sheet

41.1 Strongly disagree vs Strongly agree



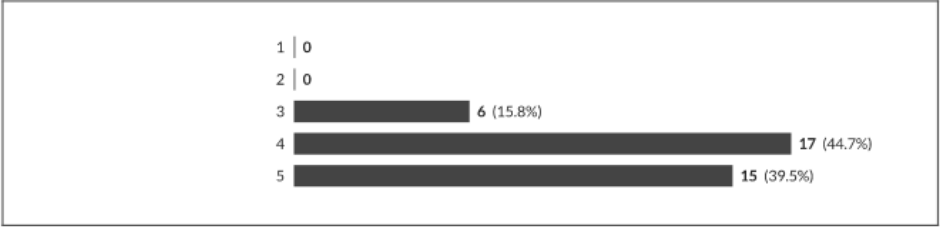
42 I was asked to provide outcomed GAS targets

42.1 Strongly disagree vs Strongly agree



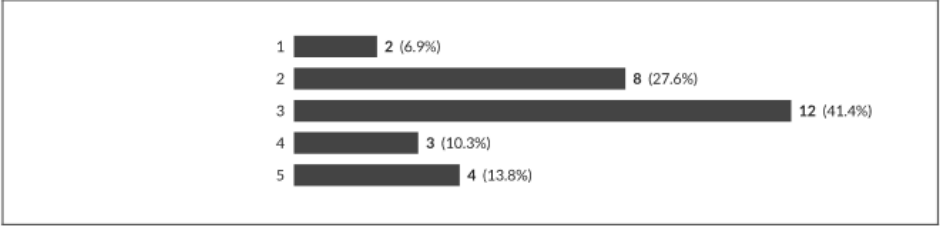
43 This research is highly relevant to my job

43.1 Strongly disagree vs Strongly agree



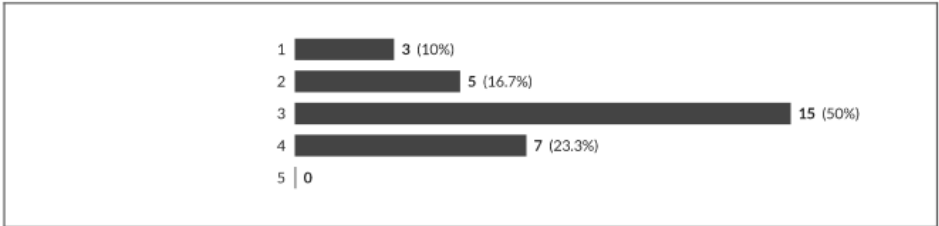
44 I was asked to provide information on attendance

44.1 Strongly disagree vs Strongly agree



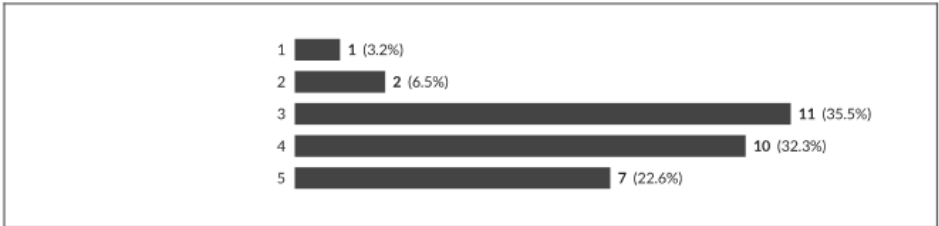
45 I enjoyed participating in this research

45.1 Strongly disagree vs Strongly agree



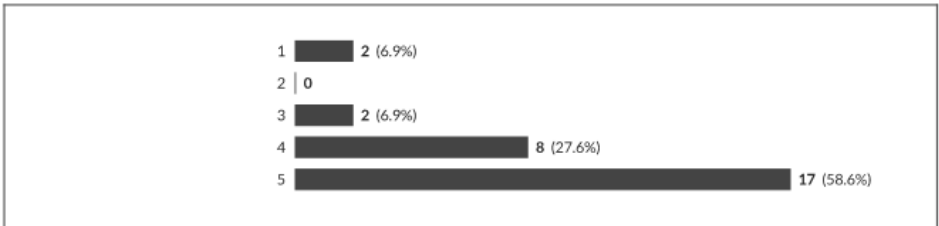
46 My manager understood what was expected of me during the research.

46.1 Strongly disagree vs Strongly agree



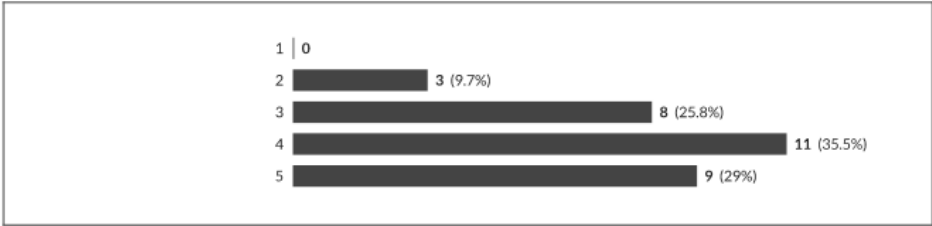
47 I was asked to provide recommendations for home practice

47.1 Strongly disagree vs Strongly agree



48 The researcher was helpful

48.1 Strongly disagree vs Strongly agree



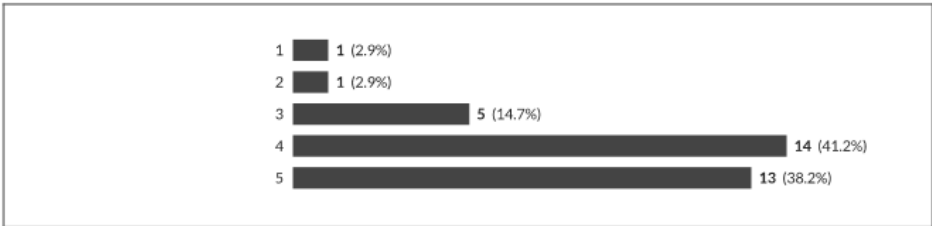
49 I was asked to provide results of any kind of assessment done

49.1 Strongly disagree vs Strongly agree



50 Email communication about the research was easy to understand

50.1 Strongly disagree vs Strongly agree



51 The research was all about our speech therapy service

51.1 Strongly disagree vs Strongly agree

