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Abuse, Neglect And Loss Of Dignity In The Institutional Care Of Older People

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Abuse, Neglect And Loss Of Dignity In The Institutional Care Of Older People

Summary of findings and recommendations

This study comprises part of a wider programme of research; *The Abuse, Neglect and Lack of Dignity in the Institutional Care of Older People Research Initiative*. It follows, and builds upon, a series of related studies:

- *The UK Study of Abuse and Neglect of Older People: Prevalence Survey* (O' Keeffe et al., 2007).
- *The UK Study of Abuse and Neglect of Older People: Qualitative Findings* (Mowlam et al., 2007)
- *Abuse and Neglect of Older People: Secondary Analysis of UK Prevalence Study* (Biggs et al., 2009)
- *Measuring the Prevalence of Abuse of Older People in Care Homes: A Development Study* (Purdon et al., 2007).

The specific aims of this study were, with a focus on residential and nursing care, to:

- map existing definitions and descriptions of abuse, neglect and dignity in institutional care
- explore the potential for these to form the basis of, or inform, robust and practical survey definitions
- consider the implications of prospective definitions for survey design and implementation
- clarify the choices that need to be made in order to move from existing definitions and descriptions to robust and transparent operational survey definitions
- where appropriate, make specific recommendations and provide guidance for developing survey definitions
- consider the implications of findings from this study for future theoretical development in this area (reported on in an accompanying paper).

The discussion and proposals in this report drew upon the following consultation and research activities:

- mapping of existing definitions and descriptions of abuse, neglect and loss of dignity in a range of policy, practice, academic and other literature
- a day-long workshop with an Older People and Carers' Advisory Group
- a day-long stakeholder event involving policy-makers, practitioners, providers, academics and experts by experience
- interviews with two researchers (Professor Catherine Hawes, USA; and Professor Thomas Goergen, Germany)
- six interviews with care home residents and some of their family members
- ongoing team discussions.

For ease, the report follows the convention of using the word mistreatment to refer to all harms; abuse, neglect and loss of dignity.

The problem of definitions

- Debate in this area abounds with abstract concepts. This includes the concepts of abuse, neglect and loss of dignity as well as embedded concepts such as de-personalisation, privacy and trust. There is no agreement about exactly what these concepts mean and existing definitions are criticised for being vague, subjective and imprecise.
- It is likely that many of these concepts are 'essentially contestable' (Gallie, 1966) with wide-ranging agreement about a core meaning and standard cases but no consensus about their complete and precise content. Attempts to identify exactly what these concepts *really* mean therefore are likely to be unhelpful
- However, at an operational level, by focusing on core areas around which there is most agreement, definitions of abuse, neglect and loss of dignity that adequately and defensibly represent these concepts can be drawn.
- There are universal definitions of abuse, neglect and loss of dignity that summarise these concepts in a short statement and descriptive definitions that identify specific behaviours and experiences. Descriptive definitions are more helpful for developing detailed survey definitions
- If operational definitions are as specific, concrete and unambiguous as possible there can be agreement about what *is* being measured, even if there remains disagreement about what *should* be measured

Trust, intentionality and age

- There is a consensus that mistreatment is defined as occurring within relationships involving trust. The concept of trust, however, remains vague and imprecise
- Position of trust is summarised as a recognised obligation or duty towards someone in a less powerful position. It was found to be a more transparent, robust and operationalisable concept than other more subjective notions of trust. It is highly relevant in an institutional setting and covers all forms of care-giving, the routines and practices within the care home and the maintenance and management of the care home environment
- Family members who provide informal care, manage a resident's affairs or finances or otherwise have privileged access to a resident and their belongings are in a position of trust. A familial relationship in itself is not sufficient. The vulnerability of residents on account of their care-dependency, however, suggests that all visitors to the home could be considered to be in a position of trust in a broader sense. We propose that 'circles of trust' based on these narrower and broader definitions of

position of trust are used for reporting findings

- Incidents perpetrated by residents, towards other residents or staff, should be asked about and reported - they indicate the level of conflict in a home and resident 'aggression' has been found to be associated with higher levels of reported abuse. However, these should not be called, or confused with, abuse and should be reported separately
- The survey should reflect a balance of concern between perpetrators' intentions and the impact on residents. It should focus on incidents where the perpetrator knew, or could reasonably have been expected to know, that their action or inaction would, or could, cause harm
- Age in itself does not make an older person vulnerable. Care home residents, however, are likely to have much higher levels of ill-health and dependence than older people in the community. As intensive service users, they will also be more vulnerable to service failure
- When reporting, researchers should use the term 'residents' rather than 'older people' since the sample is one of residents and excludes older people not living in residential or nursing care
- While it is important to gather information about victim characteristics thought to be associated with mistreatment, researchers should also gather information about perpetrator characteristics, the context of mistreatment and care home characteristics for a comprehensive and rounded consideration of risk factors

Categories of mistreatment

- With minor adaptations, the financial, psychological, physical and sexual abuse categories used in the community survey are transferable to a care home setting and can cover loss of dignity. Neglect remains a problematic category; tending to be over-inclusive and hard to distinguish from abuse
- It will not be feasible to ask about individual acts of neglect given the potentially large number of these in a care home setting. A preferred approach is to ask general questions about key areas of care making reference to specific examples. We make proposals for questions covering toileting; personal care and hygiene; hydration and nutrition; socialising; communications; medical care; physical handling; privacy and requests for assistance
- It is difficult to identify perpetrators of neglect in a care home setting since it will often be unclear who should have provided the assistance and organisational factors may also play a direct role in failures to provide aspects of service adequately or at all

- Consultation and engagement with service users and relatives and adequate redress for alleged incidents of abuse, neglect and loss of dignity will be of special interest and requires a separate category

Subjectivities, qualifiers and thresholds

- A lack of clear definitions can lead to the inclusion of inter-personal conflicts and substantive disputes. Focusing on professional relationships involving position of trust may remove ambiguity since behaviours such as swearing, insulting, belittling or pushing will always be inappropriate in these relationships. However, these behaviours may reflect 'normal' expressions of conflict in personal relationships. Respondents may need reminding of frequency thresholds and qualifiers could be additionally included alongside thresholds to provide a measure of 'density'.
- Individuals may appear to give valid answers to questions but understand the same terms differently. Privacy, for example, was found to be subject to different interpretations. Care needs to be taken to clearly define all abstract concepts in highly concrete terms
- A view was expressed that it was important to know how many people *feel* they have been abused and the dignity agenda, in particular, places considerable emphasis on subjective responses and impact. However, behaviours defined in terms of their subjective impact (e.g. '*being made to feel worthless or a nuisance*') can confuse concrete behaviours and the subjective reactions to them. Questions about subjective responses should be asked separately to questions about behaviours
- Responses about subjective impact can be difficult to interpret and factors such as existing problems, low expectations and fear of reprisal can influence how people assess their experiences. Survey questions about subjective impact should only be included where their value is clear. More extensive exploration may be undertaken using qualitative methods
- Qualifiers such as 'excessive' or 'unnecessary' are needed to define abusive behaviours that are routine or legitimate when carried out appropriately but can require respondents to make subjective judgements and may require specialist knowledge. Some terms such as '*roughly*' as in '*handled roughly*' may not appear to be qualifiers at first but effectively act as qualifiers. To maximise consistency of interpretation, survey questions should provide further guidance to residents in the form, '*by excessive we mean ...*'
- Frequency thresholds exclude one-off, less serious incidents whilst at the same time recognising the cumulative effects of repeated low level harms. They are concrete and quantifiable although where they are set can appear arbitrary. They will continue to have an important role in a survey of abuse, neglect and loss of dignity in care home settings.

- Acts that require just one act to be defined as mistreatment may be more likely to merit abuse or criminal procedures. Numerous but less immediately serious incidents are more likely to suggest organisational failings and poor care standards and the need for organisational remedies such as improved staff training or increased staff levels.

Length, scope and answerability

- Estimates from residents and their families on manageable interview length ranged from 15 minutes to 35-40 minutes, with few residents thought to be able to sustain an interview at the upper limit. Interviews also often need to be paced to meet the needs of potentially frail residents and it can take a long time to cover a small number of questions
- Introductory questions are needed to screen for cognitive impairment and neutral questions should be used to 'close down' an interview. Possible areas of inquiry are numerous and some issues may require multiple questions. This suggests a need to heavily focus on issues of key interest and to accept that all areas of mistreatment cannot be feasibly covered in a resident interview.
- There exists no ultimate list of core measures that should be covered. However, researchers should take into account the reasonableness criterion of the perpetrator knowing, or being reasonably expected to know, that their action or inaction would cause harm. They should include a range of different types of mistreatment, various areas of care and activity and strike a balance between more serious and lower level incidents. They should focus on those areas that residents are most able to provide accurate and robust information about and on behaviours that most people agree constitute relatively unambiguous examples of mistreatment.
- The questionnaire should be piloted and checked against the concerns of residents; for example, having staff knock on a door before entering was not important for some residents interviewed for this study although it is often cited as a marker of being treated with dignity
- Time periods/ frequency recall is likely to be challenging for those living in care homes and there are few markers which might help residents 'anchor' their experience to a specific time. Residents may also not have the relevant knowledge to answer some questions such as questions about over-medication.
- Gaining estimates using alternative respondents will be challenging. It was thought that residents' knowledge about the treatment of other residents may often be limited. Family and friends may not go into bedrooms or be present during care-giving and evidence suggests that their knowledge of their relative's care is not always very detailed. Training of interviewers to

select the most appropriate alternative respondent and rigorous questionnaire development and testing will be highly important.

Organisation

- The approach in the community survey was to view mistreatment as consisting of one-on-one incidents, involving identifiable perpetrators with perpetrator groups drawn so as to exclude incidents related to general service failure. However, an exploration of abuse, neglect and loss of dignity in an institutional setting will inevitably involve addressing issues of service failure and poor quality care
- The organisation itself (in the form of the 'registered person') is in a position of trust towards residents with there being clear organisational responsibilities to ensure quality of care. This is over and above the obligations on individual staff members to provide good quality care. The organisation also sets a range of constraints and parameters which influence how individual staff carry out their work
- We propose that the survey gather data relating to organisational features so as to explore links with the nature and incidence of mistreatment. The intention would not be to identify 'bad homes'. Analysis would be conducted at an aggregate level with the survey sample including small numbers of respondents across a large number of homes such that it would not be possible to draw meaningful conclusions about individual homes
- In residential or nursing care, multiple incidents of mistreatment may represent repeated mistreatment by the same person or mistreatment by a range of different staff members. Each of these scenarios has different implications for policy and practice and it is important to be able to distinguish between these

Chapter 1: Introduction

Background

In 2003, the Health Select Committee acknowledged the lack of prevalence information on the abuse and neglect of elder populations and recommended that multi-disciplinary research on elder abuse should be commissioned to clarify the full extent of the problem (Health Committee, 2004; para 29). In response, in 2005, the Department of Health and Comic Relief jointly funded a national prevalence study of abuse and neglect of older people (66 or over) living in the community; *The UK Study of Abuse and Neglect of Older People: Prevalence Survey* (O' Keeffe et al., 2007). This was recently followed up with secondary analysis of the community survey data linked with Health Survey for England data (the community survey sample was originally selected from the Health Survey for England); *Abuse and Neglect of Older People: Secondary Analysis of UK Prevalence Study* (Biggs et al., 2009)

The Health Select Committee report (2004, p.14) also noted that abuse and neglect in institutional settings may be a cause for particular concern, stating that '*... a number of submissions drew particular attention to the potential for abuse to occur behind closed doors*'. Not only may residents have less immediate access to the outside world, but they may be subject to an inappropriate institutional culture, manifested in attitudes and styles of communication as well as care practices. In response, alongside the community-based prevalence survey, a feasibility study was commissioned to investigate the possibility of conducting a survey of abuse and neglect in residential and nursing home care settings; *Measuring the Prevalence of Abuse of Older People in Care Homes: A Development Study* (Purdon et al., 2007).

The UK Study of Abuse and Neglect of Older People: Prevalence Survey (O' Keeffe et al., 2007) was also followed up with a qualitative study in which in-depth interviews with 36 survey respondents were conducted (Mowlam et al., 2007). The qualitative research explored the risk factors associated with abuse and neglect; examined the impact of mistreatment on older people, their families and carers and explored the coping mechanisms that older people developed to attempt to deal with the experience of abuse or neglect. It also explored issues concerning the operational definitions of abuse and neglect used in the community survey (note: the definitions used in the community survey can be found at Appendix 1). The findings of the qualitative study, and a later article by Dixon et al. (2009), highlighted the conceptual 'slipperiness' of concepts like 'abuse' and 'neglect' and the different way apparently similar incidents were perceived by those involved. The report from the qualitative study, *The UK Study of Abuse and Neglect of Older People: Qualitative Findings* (Mowlam et al., 2007) concluded that as a result more definitional work was needed. In particular it argued that '*it would be helpful to place 'elder abuse' in the context of the wide range of related difficulties and problems experienced by older people and to clarify the rationale for distinguishing between these different experiences of neglect or difficulty.*'

These findings reflect wider commentary in studies of elder mistreatment on the lack of clarity in the definition, operationalisation or measurement of key concepts such as 'abuse', 'neglect' or 'dignity' (e.g. Brammer and Biggs, 1998; Penhale, 2003).

The feasibility study (Purdon et al., 2008) concluded that, although challenging, a survey of mistreatment with residents living in residential and nursing care was feasible and made a range of suggestions around potential survey design and implementation. However, given the difficulties of definition highlighted by the qualitative study (Mowlam et al., 2007) and other earlier studies, the Department for Health decided that *'before empirical work is undertaken in care homes it will be necessary to establish explicit and agreed definitions of key concepts and the differentiation between them'* (Tender document, 2008). As a result, this current study, *Abuse, neglect and lack of dignity in the institutional care of older people: Definitional issues*, was commissioned to explore and clarify definitional issues in advance of a prevalence survey of abuse, neglect and loss of dignity in residential and nursing care homes; making recommendations for the way in which key concepts are defined and for how operational definitions and measures are arrived at.

This study forms part of a broader research programme, *The Abuse, Neglect and Lack of Dignity in the Institutional Care of Older People Research Initiative*. This programme also includes the secondary analysis project described above and now completed (Biggs et al., 2009) along with a number of other separate, but linked, studies. The other studies are:

- *How can I tell you what's going on here? The perspectives of residents with dementia living in care homes (Dawn Brooker, University of Worcester)* - This study aims to design an observational tool which can be used to identify risk factors for mistreatment as well as protective factors.
- *Promoting excellence in all care homes (PEACH): Exploring knowledge, practices and training needs of the care home workforce (Winifred Tadd, Cardiff University)* – This study will produce guidance for policy and practice on workforce development needs in the care home sector.
- *Analysis of secondary data sources study (Jill Manthorpe, Social Care Workforce)* – This study aims to make recommendations on the use of secondary data sources on abuse and crime in care home settings.
- *Dignity and respect in residential care: Issues for Black and minority ethnic groups (Alison Bowes, University of Sterling)* – This study aims to explore the experiences of BME older people living in residential care and their experiences of abuse, neglect and loss of dignity.
- *ResPECT: Respect in providing elder care and treatment (Anne Killett, University of East Anglia)* – This study explores the organisational

factors that contribute to good care or mistreatment in residential and nursing care homes.

- *Impatient care for people with dementia: The healthcare assistant perspective (Justine Schneider, University of Nottingham)* – This study aims to understand the experiences of staff working with older people with dementia in in-patient settings
- *Dignity in practice: An exploration of the care of older adults in acute NHS trusts (Winifred Tadd, Cardiff University)* – This study is an ethnographic project investigating the provision of care for older people in acute hospital wards with an emphasis on exploring how dignity is maintained or compromised in practice.

The remainder of this chapter describes the aims and objectives of this study - *Abuse, neglect and lack of dignity in the institutional care of older people: Definitional issues* - and the methodology used. A guide to the layout of the rest of the report is also included at the end of the chapter.

Aims and objectives

The specific aims of this study were, with a focus on residential and nursing care, to:

- map existing definitions and descriptions of abuse, neglect and dignity in institutional care
- explore the potential for these to form the basis of, or inform, robust and practical survey definitions
- consider the implications of prospective definitions for survey design and implementation
- clarify the choices that need to be made in order to move from existing definitions and descriptions to robust and transparent operational survey definitions
- where appropriate, make specific recommendations and provide guidance for developing survey definitions
- consider the implications of findings from this study for future theoretical development in this area (reported on in an accompanying paper).

Methodology

The study was comprised of key research and development stages:

- The team initially mapped existing definitions and descriptions of abuse, neglect and loss of dignity with particular reference to residential and nursing care, using a wide range of literature from various professional perspectives and fields. Policy documents, guidance and standards were accessed in order to identify definitions used by central government. Academic literature included research reports, book and articles

published in peer reviewed journals. Accounts generated from other sources, such as blogs and by voluntary organisations such as Age Concern/ Help the Aged were also accessed. Although the mapping exercise was not intended to be a systematic review, several databases (ASSIA, Sociological Abstracts, Social Care Online; Social Services Abstracts) were also searched using relevant search terms. These approaches were also supplemented by general web searches to identify other policy and non academic literature.

Items were retrieved and selected according to relevance and the extent to which clear definitions and descriptions of abuse and dignity were included. In order to condense an otherwise unhelpfully large amount of descriptive material, relevant definitions and descriptions were then collated and drawn together into a table by category, area of care and type of behaviour or experience, with relevant references cited. This is included at Appendix 1. The mapping exercise also identified a range of broader themes and issues involved in defining abuse, neglect and loss of dignity for the purposes of a survey of those living in institutional care settings. These were explored further through team discussions and through later consultative events and interviews.

- A day-long workshop was held with an Older People and Carers' Advisory Group, a group of experts with relevant professional and personal experience and who were also involved in the *The UK Study of Abuse and Neglect of Older People: Prevalence Survey* (O' Keeffe et al., 2007). The workshop involved structured discussion on issues arising from the mapping exercise. In particular, it explored relevant distinctions between community and institutional settings and emerging definitions derived from the literature. There was also specific discussion around the case example of restraint and definitional issues related to this. Ideas were also sought for further examples or sources of literature.
- A day-long stakeholder event involving policy-makers, practitioners, providers, academics and experts by experience was convened. Delegates explored issues arising from the mapping exercise and from discussions conducted as part of the earlier Older People and Carer's Advisory Group workshop. In addition, the event aimed for more detailed exploration of the key challenges of undertaking survey research in institutional settings and examined issues relating to identifying different groups of perpetrators and organisational factors.
- Interviews with two researchers (Professor Catherine Hawes, USA; and Professor Thomas Goergen, Germany) were conducted to explore their own experiences of attempting survey research in care home settings and to capture relevant learning.

Thomas Goergen, in particular, discussed his multi-method research in German nursing homes (2004). These involved:

- qualitative interviews in a randomly selected sample of eight nursing homes. Interviews were conducted with a multitude of subgroups, including residents, nursing home staff, and other people who might give evidence on abuse and neglect (for more detail see Table 2)
- a questionnaire survey among nursing home staff. This survey supplied data on prevalence and incidence of elder abuse and neglect in residential care
- an analysis of cases of elder abuse and neglect in nursing homes known to law enforcement and nursing home control agencies. By using a mix of different methods, data were collected on cases which were detected and handled by criminal courts and state survey agencies.

Professor Catherine Hawes has, with colleagues, carried out a survey in Assisted Living Facilities in the US with the purpose of describing the existing supply of assisted living facilities and examining the extent to which they matched the philosophy of assisted living. She is currently engaged in a National Institute on Ageing (NIA) funded study aimed at developing and testing methods of estimating the prevalence of elder mistreatment in nursing homes and assessing the feasibility of a national elder mistreatment survey in long-term care facilities in the US.

The interviews covered:

- methods employed for developing survey questions and definitions
- sources used for identifying pre-existing questions
- approach to the issues of thresholds, levels of severity
- approaches to intentionality
- experiences of using these questions and definitions in the field
- approaches to identifying perpetrators
- approaches to, and experiences of, including those with cognitive impairments and dementia
- use, if any, of alternative and/or proxy respondents
- approach to resident on staff and resident on resident incidents
- approaches to taking into account organisational-level variables
- involvement of staff and their perspectives, as well as of other groups such as regulators, employers etc.
- length of questionnaire

The interviews were conducted by telephone. They each lasted around an hour and a half. For the interview with Prof. Thomas Goergen simultaneous notes were taken while the interview with Prof. Catherine Hawes was recorded in full, and notes were drawn from re-listening to the recording.

- Six interviews with care home residents were then conducted to further explore some of the issues directly with care home residents and in context. Family members were jointly interviewed in three cases. All six interviews were carried out in the same nursing home, one that had been involved in the earlier feasibility report (Purdon et al., 2008). We are

grateful to the manager for agreeing to extend the involvement of the home to include this study and to the residents that agreed to participate.

The interviews were conducted within the care home. Each of them lasted approximately half an hour and, with the respondents' agreement, were recorded in full. Respondents were made fully aware that their involvement was entirely voluntary, that they did not have to answer any question they did not want to, that they would not be named in any report, that the information they gave would not be attributed to them and would be reported only in the form of general findings. NatCen has an escalation procedure for any concerns about the well-being of respondents which applied to these interviews. Any case where it appears that someone is in immediate danger and cannot act for themselves can be referred to an emergency panel of the NatCen Ethics Committee and the Chief Executive who decide on appropriate action. No case from these interviews was referred. The interviews covered:

- the idea of de-personalisation with reference to staff chatting to residents while providing care
- understandings pertaining to the idea of 'rough handling'
- how far residents could answer questions related to medication, particularly whether given medication solely for the purposes of managing their behaviour
- ideas about the meaning of privacy in a residential care/ nursing home context
- expectations around the giving of intimate care and the idea of dignity in this context
- whether, and how far, relatives, visitors or other residents would be able to answer questions on their behalf and whether they would be able to provide reliable and valid answers for other residents
- what length of questionnaire would be feasible for respondents
- any other issues arising relevant to the study

Comprehensive notes were later taken from the sound recordings and key insights and learning identified through a thematic analysis

- Ongoing team discussions were an important aspect of the research process and were undertaken at all stages to draw together and discuss findings from the research and consultation activities and to explore their relevance for informing the way in which concepts might be best defined and measured in a survey of abuse, neglect and loss of dignity in residential and nursing care settings.

The report

The nature of the study and purpose of report

The researchers have approached the mapping exercise, group workshops and interviews using appropriate and rigorous research methods and have drawn systematically and comprehensively upon data and findings from these activities in order to inform their observations, arguments and proposals. However, this is different to gathering and reporting on empirical data; this report does not attempt to provide a direct account of the data derived from these research and consultation activities. Rather this report aims to set out a defensible, evidenced and reasoned approach to defining abuse, neglect and loss of dignity for a prospective survey of residents living in residential and nursing care.

What we mean by 'definitions'

Definitions exist at various levels. We establish early on (see Chapter 2) that the study does not, and cannot not, pronounce on what abuse, neglect and dignity *really* are (although, see accompanying paper on the implications of findings in this study for theoretical development in this area). Rather the focus of this report is on establishing a framework for the development of operational definitions and the survey measures and questions which reflect these operational definitions. Operational definitions take the form of short, practical and concrete statements or questions. They make concrete abstract ideas so that they can be measured in a reliable and valid way.

Conventions and terminology used in this report

In practice, there is considerable overlap between definitions and descriptions of loss of dignity with those of abuse and neglect and no clear demarcation between these, although loss of dignity covers a broader range of behaviours including less immediately harmful behaviours and behaviours defined in terms of their impact or the subjective response of the person experiencing the harm. For ease, the report follows the convention used in the community survey report of using the word mistreatment to refer to all harms; in this case, abuse, neglect and loss of dignity. Care is taken throughout to refer separately to abuse, neglect and/or loss of dignity where this is relevant.

The rest of the report sets out the findings, conclusions and proposals from the study.

- Chapter 2 describes and reflects on the problems of definition in the study of abuse, neglect and loss of dignity
- Chapter 3 explores and makes proposals concerning three definitional parameters that act to include or exclude certain experiences from being defined as abuse, neglect and loss of dignity – trust, intentionality and age
- Chapter 4 considers the categorisation of behaviours and experiences of mistreatment in the community survey and makes proposals for how these

may need to be adapted for a survey conducted in residential and nursing care settings which also covers loss of dignity

- Chapter 5 considers areas of subjective judgement involved in answering questions about abuse, neglect and loss of dignity – covering scope for subjective interpretation, qualifiers and thresholds - and makes proposals for increasing the reliability and transparency of survey measures
- Chapter 6 examines what is a viable length of interview, what range and coverage might be appropriate and feasible, including how far residents and alternative respondents will be able to provide accurate and reliable answers to questions.
- Chapter 7 considers the role of the organisation and organisational factors and how this affects the way in which abuse, neglect and loss of dignity are conceived and defined in operational terms.

Chapter 2: The problem of definitions

Universal and descriptive definitions

Existing definitions of abuse, neglect and loss of dignity can be found in two broad forms. Firstly there are universal definitions or what Stones (1995) refers to as 'connotive' definitions. These are designed to capture, in a short statement, the defining characteristics of a concept. Such definitions include, for example, the definition of elder mistreatment used by the charity, Action on Elder Abuse, and adopted by the World Health Organisation which defines elder mistreatment as:

'A single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person' (WHO, 2002, p 2).

In another example dignity is defined as:

'Dignity is an inherent characteristic of being human; it can be felt as an attribute of the self, and is made manifest through behaviour that demonstrates respect for self and others'. (Jacelon et al. 2004: P81)

Such definitions are deliberately broad and are unspecific about the particular behaviours and experiences that are included. They also often include embedded abstract notions such as 'trust' or 'respect' which require further definition. Such definitions therefore are not likely to provide the most helpful basis for developing detailed and practical survey definitions or measures.

The second form of definition covers descriptive definitions or what Stones (1995) refers to as 'denotive' definitions. These list or describe relevant behaviours and experiences. Commonly, authors have described relevant behaviours and experiences as exemplars in the context of more general discussions about elder mistreatment and have sometimes focused on specific aspects of mistreatment, such as restraint (CSCI 2008) or privacy (Department of Health, 2003) The behaviours and experiences identified are numerous and vary across authors, and viewed together, they comprise an extensive list. The following bulleted list (Box 1) is a summary of the behaviours and experiences that were identified in a mapping of the policy, practice and academic literature (see Appendix 1 for a complete list with references). They do not include behaviours defined solely by their subjective impact (e.g. being made to feel worthless or a nuisance) as these were not considered to be behaviours (discussion of subjective responses can be found in Chapter 5) and some inclusions (e.g. personal/ intimate care not provided by someone of same sex) may not be widely considered to be abuse or a loss of dignity.

Box 1: List of behaviours and experiences identified in the literature as abuse, neglect or loss of dignity

Financial

- Stealing (or attempted to steal) money, possessions or property
- Making resident (or trying to make resident) give them money, possessions or property
- Using (or trying to use) fraud to take resident's money, possessions or property
- Misuse (or attempted misuse) of power of attorney
- Family acting to ensure that resident is given lower standard of care than needed or wanted in order to maintain assets for purposes of maximising inheritance
- Not being either rehabilitated or moved to higher support care because of financial incentives for institution in keeping older person in existing care setting
- Inappropriate charging for services (e.g. bathing) and/or over-charging
- Not having (sufficient) money of own for spending including being denied opportunity/ right to access personal funds
- Not being given appropriate assistance to manage/ monitor financial affairs (e.g. help reading bank statements)
- Not being given appropriate assistance to access benefits

Psychological abuse/ neglect

- Insulting resident, calling them names, swearing at them or making unjustified accusations
- Threatening resident (e.g. to hurt them, to abandon them, with punishment etc.)
- Shouting at resident
- Undermining or belittling resident
- Making racist, ageist, sexist comments or jokes
- Staff laughing at residents, playing tricks on them and/or treating serious incidents as a joke, use of sarcasm etc.
- Impatience, being rushed and lack of courtesy
- Patronising and/or infantilising way of addressing (e.g. telling off, talking down to, speaking to in a bossy or scolding way)
- Not using requested/ desired term of address/ using overly informal or familiar terms of address
- Excluding resident or repeatedly ignoring them (e.g. 'silent treatment')
- Failing to ensure adequate level of socialisation/ inter-personal engagement
- Lack of appropriate communication methods with those with people with sensory impairments or dementia (e.g. visual aids, non-verbal communication)
- Lack of engagement with wider community/ Lack of assistance to travel outside care-home

- Lack of enhanced support at times of acute distress in a manner that takes account of resident's preferences
- Not talking, interacting while delivering care
- Staff forgetting when family and friends are due to visit and do not ensuring appropriate arrangements
- Lack of reminiscence activity for dementia sufferers
- No or few activities for residents; lack of stimulation
- Not feeling needed, not having sense of purpose/ role
- Not identifying/ using older person's skills, abilities
- Residents not being permitted to participate in/ contribute to day to day running of the home
- Not respecting individual choices about own care
- Not supporting residents to make decisions where needed, including those with cognitive or communication difficulties
- No choice in décor or furnishing of own room
- Lack of choice concerning appearance (e.g. dress/ hair)
- Not wearing own clothing
- Not having own glasses, hearing aids, dentures
- Lack of choice concerning schedule
- Lack of maintenance of respectable appearance
- Lack of sensitivity and responsiveness to culture, religion, age, disability, gender and sexuality
- Preventing resident from seeing others that they care about
- Checking up on resident (in a way that is excessive or makes them feel afraid)
- Miscellaneous bullying by other residents (e.g. residents demanding that a chair is 'theirs', hogging the TV remote control)
- Staff having hostile attitude to residents' visitors
- Being denied food or privileges as punishment
- Failure to provide adequate explanation and information, in appropriate format, free of jargon

Privacy

- Lack of privacy in personal space (bedrooms, bathrooms and toilets/ commodes) or for the giving of personal care
- Lack of single sex or en suite toilets/ bathrooms
- Staff and others not knocking/requesting permission before entering private space
- Lack of privacy for medical consultation with, and examination by, health professionals
- Lack of privacy for consultations with legal and financial advisors/ social workers
- Lack of privacy for expressions of intimacy and sexuality (with appropriate assessment of risk to vulnerable people)
- Lack of privacy in communications - when meeting with friends and relatives, mail being opened by others, not receiving mail promptly, no private use of telephone

- Lack of ability to spend time alone when wanted
- Lack of privacy of care received prior to and at time of death
- Lack of confidentiality/privacy of personal information
- Overcrowded conditions

Physical abuse/ neglect

- Slapping resident
- Grabbing, pushing or shoving resident
- Kicking, biting or hitting resident with a fist
- Hitting resident with an object
- Burning or scalding resident
- Threatening resident with (or using) a knife, gun or other weapon
- Choking or attempting to drown resident
- Other violence – (e.g. shaking, pulling hair, electric shock, exposure to noxious odours, scalding with hot water, opening windows or removing blankets at night, any other physical ‘punishments)
- Restraint – (e.g. being tied or held down, locking resident in their room, giving drugs or too much medicine in order to control resident/ to make them docile, unnecessary use of catheters, feeding tubes/ force feeding, not allowing to move freely around home or into garden, use of bed rails, chairs that person is unable to get out of unassisted, forcibly moving someone or preventing them going where they want)
- Being handled roughly during giving of care
- Ignoring calls/ requests for assistance/ call button
- One rather than two person transfers
- Lack of appealing, good quality food; poor nutrition
- Lack of availability of food/ snacks between meals
- Residents being rushed to eat and drink/ interruptions to mealtimes
- Lack of appropriate and dignified assistance to eat food/ drink
- Lack of freely available and accessible drinking water
- Failure to address significant weight loss (e.g. measuring food and fluid intake)
- Lack of consultation on menus with residents; taking account of individual preferences
- Lack of clean, tidy environment free from unpleasant odours
- Environment not adapted to needs of residents (e.g. those with mobility impairments)
- Not being given needed medication/ medical attention (including hearing aids, glasses and prostheses and oral/ dental care)
- Being given insufficient information about medication
- Attending medical appointments without staff ensuring relevant information/ paperwork or bringing residents at the wrong time
- Lack of adequate pain control
- Being given too much or too little medication
- Staff forgetting when professionals are due to visit and do not ensure appropriate arrangements

- Failure to gain professional advice for behaviour such as extreme distress, anxiety, aggression
- Failure to take action to prevent bed/ pressure sores
- Not being appropriately dressed; too hot or cold
- Insufficient exercise/ not doing 'range of motion' exercises
- Residents not being supported to have good personal hygiene
- Leaving residents in the toilet, on a commode for an extended period of time
- Being forced to use a commode rather than be helped to bathroom
- Taking life (method not specified in literature)

Sexual

- Talking to resident in a sexual way that made them feel uncomfortable (serious teasing, innuendo, harassment)
- Making resident (or trying to make resident) watch pornography against their will (or in situation where resident could not give consent)
- Coerced nudity, voyeurism 'peeping tom' behaviour
- Non-consensual sexually explicit photographing
- Indecent exposure
- Touching resident (or trying to touch resident) in a sexual way against their will (or in situation where resident could not give consent)
- Having (or trying to have) sexual intercourse with resident against their will (or in situation where resident could not give consent)
- Penetrating vagina, anus, mouth (or attempting to penetrate) with penis, fingers or objects against will (or in situation where resident could not give consent)
- Attacked sexual parts
- Inappropriately intimate touching of residents during administration of care
- Personal/ intimate care not provided by someone of same sex

Other

- Lack of systems available for complaining about services that residents are aware of and know how to access
- Lack of systems for raising alert to potential abuse/ neglect
- Lack of support to access complaint system if needed
- Complaints not appropriately and promptly handled.

The descriptive definitions identified in Box 1 vary in how closely they are specified or described in the literature, with these ranging from existing survey questions and detailed and specific descriptions to, far more commonly, broad and general references. However, descriptive definitions appear to be potentially more fruitful than universal definitions as a starting point for identifying and developing prospective survey definitions and measures.

Lack of agreement on the meaning of key concepts

Undertaking a survey of residents living in institutional care settings is a challenging undertaking. As with any survey, the operational definitions and survey questions need to be clear, consistently understood, relevant and fit for purpose and any underlying issues or difficulties with terms and concepts need to be explored and resolved early on. This is a particular consideration in a survey of abuse, neglect and loss of dignity since the area abounds with abstract concepts that need to be operationalised so that they are concrete and measurable. These include the broad concepts of abuse, neglect and loss of dignity as well as a range of embedded concepts such as, for example, de-personalisation, privacy and trust.

How these abstract concepts are operationalised in a survey is highly important, since *'different definitions of mistreatment obviously produce differing estimates of prevalence'* (Biggs et al., forthcoming). However, there is no general agreement on exactly how these concepts should be defined with multiple research definitions in use, drawn from a range of different legal, policy, practice, stakeholder, interest group and academic contexts (Briggs and Brammer, 1998; Bonnie and Wallace, 2003). *Raising Voices* (CSCI, 2008, p.49), for example, identified a lack of clear definitions concerning the safeguarding of adults, stating that *'There is no shared understanding of what 'safeguarding adults' means, and no generally accepted definitions for several words that apply to safe-guarding adults situations: 'safeguarding', 'abuse', 'harm' and 'vulnerable'*. The plethora of meanings for these various terms can lead to definitions becoming *'so wide as to be over-inclusive and lose meaning'* (Biggs et al., forthcoming). Hawes (2003, p. 477) points to the fundamental nature of the difficulties when she says *'determining what the focus of future research should be is challenging; one challenge involves defining the nature of the phenomenon'*.

Dignity in care is an area with even less precise definitions. The literature on dignity in care overlaps with that of abuse and neglect but covers a wider range of issues, including a greater number of less immediate and serious experiences and behaviours and definitions also more frequently drawn with reference to subjective judgements about psychological and emotional impact and additional abstract notions. For example, Chan (2004, pp. 228-229) defines dignity as being *'about living respectfully, characterized by equal human value, the use of autonomy, self respect, as well as societal respect'*. Payne (2008), however, refers to the dignity literature, commenting that, *'my impression of a lot of this work is that it is circular; a small group of terms like esteem, respect and dignity are used to define each other with no real clarity about what people mean by them'*.

This lack of clarity about terms results in an effective confusion about what is being measured and confusions in associated discussions about the nature and prevalence of mistreatment. Biggs et al. (2007, p.11) observe that, *'differences in definition have posed a longstanding problem in the scientific, policy and practice literature on elder mistreatment, giving rise to considerable variation in assessments of prevalence and the risks that older people may*

face' and that this *'has lead to confusion and sometimes heated debate about the nature and extent of mistreatment'*.

Moving towards clearer definitions

There is evidently a need for clear and agreed upon definitions. However, it seems entirely possible that many of the concepts in this area are 'essentially contestable' (Gallie, 1966). An essentially contestable concept is one where there is general agreement about the existence of the concept and its core meaning but disagreement about the full and precise content of the concept. Essentially contestable concepts are abstract, internally complex and deliver value-judgements. Dworkin (1972, pp. 27-28) illustrates the idea using the concept of fairness. He asks us to imagine a group that share the view that certain acts are unfair and that the members of this group *'agree on a great number of standard cases of unfairness and use these as benchmarks against which to test other, more controversial cases'*. The members may still disagree over many of these *'controversial cases'* because they have different understandings about why each of the agreed upon *'standard'* cases constitutes a genuine act of unfairness. In the case of an essentially contestable concept, no one of these understandings has an obviously greater claim to be considered the most accurate or appropriate. Concepts such as 'abuse' or 'dignity' and many of the embedded concepts appear also to function in this way (Dixon et al., 2009). This can make it difficult, if not impossible, to agree about over-arching definitions or, where there is apparent agreement, this may be a superficial agreement with no clear and shared understanding about exactly what this means in practice. To the degree that these concepts are essentially contestable attempting to identify exactly what these various concepts *really* mean or *really* consist of will be unhelpful. It is, therefore, not an objective of this study to attempt to identify final and authoritative over-arching definitions of abuse, neglect or loss of dignity or of other abstract embedded notions.

To the degree that high level definitions of abuse, neglect and loss of dignity are needed – to provide the focus for, and to describe, the survey research - these should be based on simple, clear and brief descriptions of the frameworks, processes and criteria used to select operational measures. This would, for example, take the form, 'by abuse we mean ... '. We do not attempt to provide these definitions here since they will depend on the choices made by a survey team in light of consultation on specific measures and upon questionnaire development and testing. However, we would expect them to be broadly based on established current definitions such as the WHO definition (2002) but propose, for example, that they include a clearer notion of trust based on position of trust (as a recognised obligation towards someone less powerful) and a criterion of 'reasonableness' such that included behaviours would be those that a perpetrator knew, or would reasonably be expected to know, would or could cause harm. These issues are discussed in more depth later in this report. However, we believe that keeping over-arching definitions as descriptive as possible for the purposes of a prospective survey will ensure

that they are less ambiguous, more grounded in the data being collected and more transparent. As well as making the focus of the research clearer, we believe that this transparent approach provides more fertile ground for refining definitions and theory in this area in the future.

Critically, however, we do believe that the concepts of abuse, neglect and loss of dignity can be defined a way that is clear and defensible at an operational level. By and large there is widespread agreement over a range of behaviours and experiences thought to be abusive, neglectful or to represent a loss of dignity. These are likely to consist of the more 'standard cases' in Dworkin's example. Where disagreement exists, this tends to be over more controversial or marginal cases and over what constitutes a definitive range of behaviours and experiences. Sometimes this disagreement is reflective of an ongoing lack of clarity around key parameters such as trust and intent – we make proposals here concerning clearer definitions of trust based on the idea of position of trust and the reasonableness criterion described above as an appropriate measure of intent. Consequently, for all practical purposes, we believe that operational definitions of abuse, neglect and loss of dignity can be drawn to adequately and defensibly represent these concepts. We aim in this report, therefore, to provide a coherent approach to defining and measuring these concepts; one that is consistent, transparent and robust and that produces estimates that can be compared, as far possible, with similar research.

Certainly, previous attempts to establish clear and transparent research definitions have frequently been challenging. Findings from a follow-up qualitative study to the community survey (O' Keeffe et al., 2007) point to a range of difficulties in operationalising the concepts of elder abuse and neglect for the purposes of research (Mowlam et al., 2007; Dixon et al., 2009). In particular, the study identified problems in operationalising the notion of 'expectation of trust' (WHO, 2002) in a way that was clear and consistent and also drew attention to the subjectivity and inclusivity of some behavioural definitions, particularly in the case of psychological abuse and within familial and personal relationships. Given these challenges, we believe that it is important for research definitions to be as specific and concrete as possible so that meanings are clear and to ensure robust and understandable results. This should facilitate agreement about what *is* being measured even if there inevitably remains disagreement about what *should* be measured.

This places key importance on the process of questionnaire development to ensure that questions are clear, specific and unambiguous. It also places an emphasis on sustaining conceptual clarity, consistency and coherence and the need to guard against developing research definitions by adding in more instances and criteria because different things 'feel' like abuse or in response to different stakeholder arguments and interests. It further places emphasis on developing shared understandings between the survey team and the sponsors and stakeholders about exactly how abstract concepts are being conceived and operationalised (and how they are not). It will also be important in reporting findings that abstract terms are always clearly and explicitly rooted in, and defined by, the specific questions used to measure them to avoid

misunderstandings or unwarranted extrapolations about what the figures represent. We believe that increasing the transparency of key concepts and how they are operationalised will ultimately contribute to constructive debate and discussion about definitions of abuse, neglect and loss of dignity for research in the future.

Finally, for all the abundance of abstract concepts and terms, the field of elder mistreatment has been criticised for being poorly theorised. For example, the National Research Council (Bonnie and Wallace, 2003) describes definitions in this area as *'largely descriptive and pragmatic, taking the concepts and definitions used in practice or in statutes as given, rather than deriving the concepts and measures from theoretical premises or hypotheses. The atheoretical nature of the research is reflected in the tendency to lump all forms of mistreatment into a single category.'* The authors of this report recognise this lack of theoretical development and an accompanying paper to this report makes a range of observations about the theoretical implications of this study's findings and how these might inform theoretical development in this area in the future.

Key points and recommendations: The problem of definitions

- Debate in this area abounds with abstract concepts. This includes the concepts of abuse, neglect and loss of dignity as well as embedded concepts such as de-personalisation, privacy and trust. There is no agreement about exactly what these concepts mean and existing definitions are criticised for being vague, subjective and imprecise.
- It is likely that many of these concepts are 'essentially contestable' (Gallie, 1966) with wide-ranging agreement about a core meaning and standard cases but no consensus about their complete and precise content. Attempts to identify exactly what these concepts *really* mean therefore are likely to be unhelpful
- However, at an operational level, by focusing on core areas around which there is most agreement, definitions of abuse, neglect and loss of dignity that adequately and defensibly represent these concepts can be drawn.
- There are universal definitions of abuse, neglect and loss of dignity that summarise these concepts in a short statement and descriptive definitions that identify specific behaviours and experiences. Descriptive definitions are more helpful for developing detailed survey definitions
- If operational definitions are as specific, concrete and unambiguous as possible there can be agreement about what *is* being measured, even if there remains disagreement about what *should* be measured

Chapter 3: Trust, intentionality and age

There were a number of early decisions about definitions that the researchers developing the *UK Survey of Abuse and Neglect of Older People in the Community* (O' Keeffe et al., 2007) needed to make. These included decisions about criteria that needed to be met before any particular behaviour or experience could be considered to be included within the definitions of abuse and neglect. In particular, the researchers had to consider:

- whether, and how, to include the notion of mistreatment as occurring in relationships involving trust, and
- whether, and how, to take account of the intentions of the perpetrator.

We discuss the approach to these issues taken in the community survey (O' Keeffe et al., 2007) and in the secondary analysis study (Biggs et al., forthcoming) and explore the most appropriate approach for a survey of abuse, neglect and loss of dignity in residential and nursing care settings.

The researchers on the community survey also needed to define 'older person'. We consider the relevance of age in elder mistreatment, the relationship of age to risk of mistreatment and reflect on the resulting implications for a survey of older people living in residential or nursing care settings.

Expectation of trust

The concept of trust in definitions of elder mistreatment

Trust was not a defining feature in early definitions of elder mistreatment. The Government guidance, *No Secrets* (HMSO, 2000) and the equivalent guidance in Wales, *In Safe Hands* (Social Services Inspectorate for Wales, 2000) took the view that, '*Abuse may occur in any relationship*' citing a wide range of potential perpetrators including, '*relatives, family members, professional staff, paid care workers, volunteers, other service users, neighbours, friends and associates, people who deliberately exploit vulnerable people and strangers.*'

However, later it was argued that abuse and neglect should be defined as taking place within relationships involving 'trust'. This was articulated in the WHO (2002) definition, which defines elder mistreatment as occurring in relationships within which there is '*an expectation of trust*', drawn from a definition developed by the UK charity, Action on Elder Abuse in 1995. The National Research Council (Bonnie and Wallace, 2003, p.40) later defined elder mistreatment as being perpetrated '*by a caregiver or other person who stands in a trust relationship to the elder*' and described the idea of trust as '*central*' to this area of research. However, despite a growing consensus that

the definition of elder mistreatment should focus on harms occurring in relationships involving trust, the concept has remained vague and imprecise.

The community survey (O' Keeffe et al., 2007) drew upon the WHO definition, and aimed to restrict the definition of mistreatment to harms perpetrated in relationships involving an 'expectation of trust'. The researchers operationalised this by only including in estimates of mistreatment harms inflicted by certain categories of perpetrator – spouse, family member, care worker and close friend – and excluded similar behaviours carried out by neighbours, acquaintances and strangers. This approach was taken in an attempt to reflect existing thinking about relationships involving trust and to provide as much comparability with previous surveys as possible. This approach was somewhat adapted in a follow-up secondary analysis project which involved conducting further analysis of the community survey data (Biggs et al., forthcoming). In this later study, inner and outer circles of trust were identified, with family, friends and carers in the centre and neighbours and acquaintances constituting an outer circle of trust. The issue of how trust is operationalised in practice is an important one since how widely perpetrators of mistreatment are defined will, *'generate different levels of prevalence, even when the population of respondents remains the same.'* (Biggs et al., forthcoming, p.65).

Mowlam et al. (2007) and Dixon et al. (2009), in their qualitative follow-up study to the community survey, identified a range of problems for operationalising the concept of trust for research. They found that the bases for distinguishing between relationships involving and not involving an expectation of trust were unclear and found a specific confusion between the idea of 'position of trust' (sometimes referred to as a 'relationship of trust' or 'trust relationship') and a more extended concept of trust, which was more subjective and based on affective trust. Biggs et al. (forthcoming, p.69), summarise these findings, arguing that *'position of trust is currently used as if it is an amalgam of legal duties, professional codes of practice, degrees of intimacy and interpersonal relationships.'* Of these different conceptions of trust, the qualitative study concluded that position of trust was a relatively robust and well-established concept, particularly as it applies to paid care workers and informal carers. However, they found that the more extended notion of trust was vague and under-specified and that the bases for assuming particular categories of relationship to involve this extended idea of trust were often unclear and did not always correspond to older people's experiences. This extended form of trust could also be fluid, conditional, partial and context-dependent and therefore unhelpful as either/or criterion for determining whether a behaviour constitutes mistreatment. We believe, therefore, that position of trust is the clearer and more robust conception of trust for informing research definitions.

Position of trust

'Position of trust' (and related terms that are used synonymously such as 'relationship of trust' or 'trust relationship') are widely used terms with legal

application. They can apply to both formal and informal relationships whereby one party is considered to be in a position of relative power or authority to the other. There is no singular definition of the concept, with varied definitions set out in a range of legal or semi-legal contexts. For example, the offence of 'abuse of a position of trust' is set out in the Sexual Offences (Amendment) Act 2000 and The Sexual Offences Act 2003 and residential care homes are specifically mentioned as settings within which this offence could apply. Abuse of position of trust is also commonly referred to in sentencing guidelines as an aggravating factor for the purpose of assessing the seriousness of an offence (Sentencing Guidelines Council, 2004., p.6).

A further, and highly relevant, definition of position of trust, here referred to as 'relationship of trust', is set out in the Home Office publication, *Caring for Young People and the Vulnerable: Guidance for Preventing Abuse of Trust* (Home Office, 1999, p.4). This states that '*broadly speaking, a relationship of trust can be described as one in which one party is in a position of power or influence over the other by virtue of their work or the nature of their activity*'. However, the guidance goes on to suggest that '*such a wide interpretation goes beyond what is reasonably defined as a relationship of trust*' and proposes that the definition is limited to '*where the other party is particularly vulnerable*', thus introducing the additional concept of vulnerability.

Reflecting the considerable debate there has been around the idea of vulnerability, the guidance (Home Office, 1999, p.3) states, '*There is no simple definition of a vulnerable adult based on age or disability. For example, there is no one age at which elderly people should be classed as vulnerable and many would rightly resent such a classification. Nor could or should all those with physical or other disabilities be classed as vulnerable.*' The Law Commission (1997, pp.27-28) provides a much cited definition of a vulnerable adult, stating that it is a person who '*is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation*'. For our purposes, this definition of vulnerability would seem to cover the majority, if not all, residents living in residential or nursing care settings. The Home Office (1999, p.3) is even clearer about the vulnerability of residents in residential and nursing care services and the responsibilities of service providers and relevant professionals, stating that there are '*certain services provided for adults where the service providers are in a particular relationship of care to all those receiving such services, the majority of whom are likely to be vulnerable*' and specifically cites residential care services as one such service where this applies. The Home Office guidance further notes that, '*In some professions, such as medicine, nursing, education or social services, all relationships with patients/pupils/clients are founded on trust*' (p.5).

The idea of 'position of trust' (otherwise referred to as 'trust relationship' or 'relationship of trust') seems to be highly applicable in a survey of older people living in residential and nursing care settings, with individual staff, volunteers, visiting medical, social service, care and related professionals and the organisation itself having clear responsibilities and duties of care towards

residents. This would cover all forms of care-giving in residential or nursing care settings, the routines and practices within the care home and the maintenance and management of the care home environment.

The idea of 'position of trust' also provides a well established, transparent and robust concept of trust upon which to base survey definitions of abuse, neglect and loss of dignity. It conceives of trust as a recognised obligation or duty towards someone in a less powerful position and is thus distinguishable from more general, subjective and affective notions of trust, which are vague and imprecise and can be too readily stretched to include harms carried out by an overly wide and diverse and range of perpetrators. It is thus a helpful concept to distinguish abuse from a wide range of other harms. Hence being attacked or robbed by a stranger or an acquaintance is assault or theft but not physical or financial abuse. However, harms inflicted by those who have a formal relationship of trust or those who have otherwise assumed responsibilities and duties of care towards the victim, is both an assault or theft *and* physical or financial abuse.

By these definitions, residential and nursing care homes and their staff, volunteers and medical, social services, care and other relevant professionals are unambiguously in a position of trust towards residents. However, the idea of position of trust can be drawn more widely than these organisational and professional roles, to encompass family members and others. The nature of the concept, however, is that the more widely the concept is drawn, the fuzzier the concept becomes at the margins.

Family and the notion of trust

A social norm of reciprocity, support or affective trust within families is sometimes cited as a reason for having an expectation of trust towards family members in general. Giddens, 1990, p.101) says '*kinspeople can usually be relied upon to meet a range of obligations more or less regardless of whether they feel personally sympathetic towards the specific individuals involved*'. However, this view of the family conflicts with a range of alternative conceptions, with analyses within the fields of feminism (e.g. Okin, 1989) and, indeed, elder abuse itself commonly conceiving of the family as a potential site of abuse and oppression (Chappell et al., 2003; Biggs and Powell, 2001). The follow-up qualitative research to the community survey (Mowlam et al., 2007; Dixon et al., 2007) found that family relationships were highly variable in the degree to which affective trust or an expectation of support existed in practice. Relationships with low levels of affective trust were found often to be those involving more distant family members or members of reconstituted families but there were also numerous examples of low levels of trust in relationships with more immediate relatives. For these reasons, it does not seem that this more extended notion of trust, based on assumptions about affect and expectations of support in family relationships, provides a helpful conception of trust in research definitions.

The concept of position of trust does not necessarily apply to family members either. Family members who provide informal care to a resident, who oversee their affairs or otherwise have privileged access to a resident or their finances and possessions (e.g. a spouse) would fairly clearly be in a position of trust. Other family members may be regular visitors and provide ongoing social and inter-personal support and, on this basis, could perhaps be considered to hold a position of trust although this appears to sit towards the margin of the definition. Family members who do not meet the above definitions are not, on the basis of their relationship with a resident, in a position of trust. To consider them such would, in the words of the Home Office guidance (1999) '*go beyond what is reasonably defined as a relationship of trust*'. As a result harms committed by these family members, while potentially abusive or undignified in a lay sense, do not constitute mistreatment in the narrower sense of occurring within a relationship of trust and comprising an abuse of that trust. However, the vulnerability of residents, in terms of their care-dependency, could be used to argue that all visitors to the home are in a broad position of trust towards residents. Consequently, family members without the specific responsibilities that would place them in a position of trust could still fall within this broader definition of position of trust.

We propose that harms perpetrated by *all* family members, regardless of the extent to which they are in a position of trust, are included in a prospective survey. The resulting estimates would ideally be reported on the basis of whether the family member was clearly in a position of trust (whether they provide informal care, manage residents affairs or otherwise have privileged access to a resident, their finances or possession or, potentially, on the basis of regularity of contact) or whether they might be considered to be in a position of trust only in the broader sense (because of residents' vulnerability). However, in the context of a survey, it could be difficult to distinguish these different types of family relationship and the boundaries between these different types of relationship may also often be 'grey' and inconsistent. The survey researchers should consider whether screening questions would be feasible in order to enable a distinction to be made between these different groups of family members. If this proves infeasible (due, for example, to lack of questionnaire space or because of difficulties in constructing suitable questions) we would propose that estimates for harms committed by family members are reported together.

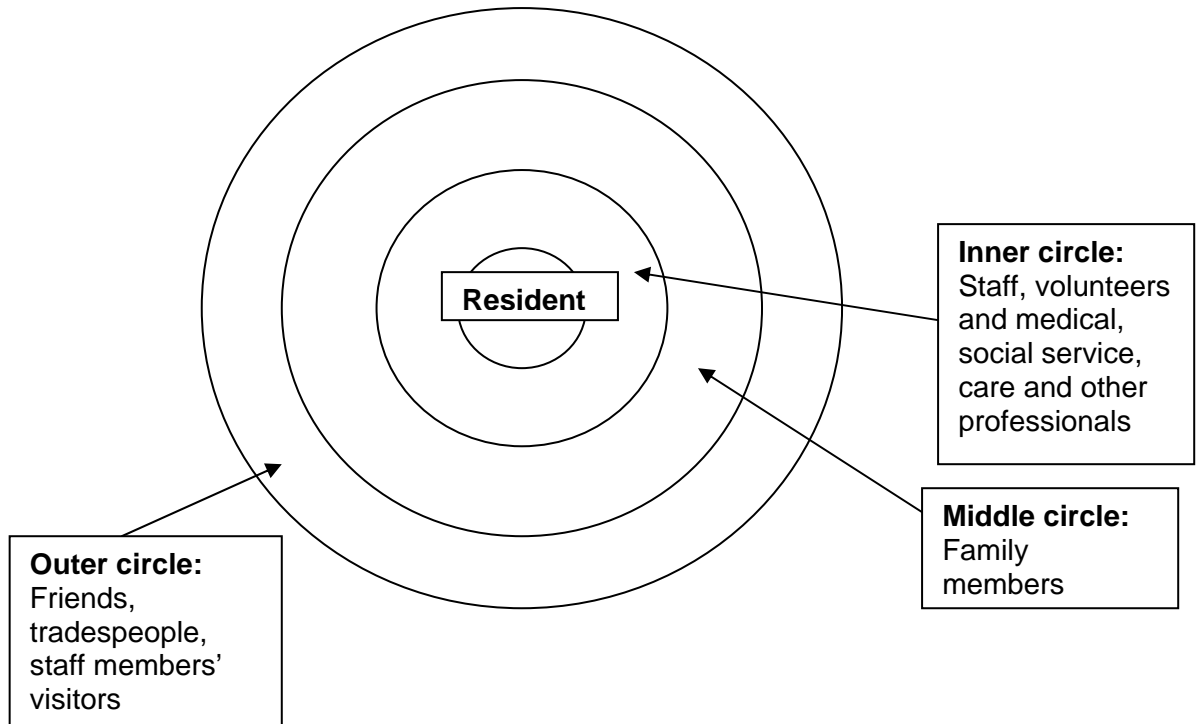
Circles of trust

We believe that the approach taken in Biggs et al. (forthcoming) of constructing inner and outer circles of trust is a helpful one. Care home staff and volunteers, along with medical, social services, care and other related professionals, would comprise a core group of individuals who stand unambiguously in a position of trust towards care home residents. Family members providing informal care, managing a resident's affairs or with privileged access to a resident, their finances and possessions might also be included in this inner circle of trust. Family members who are regular and frequent visitors could potentially also be placed in this same group.

If it is not possible to distinguish between different types of family relationship, incidents perpetrated by family members could be allocated as a whole to either an inner or outer circle. There are arguments for each of these approaches. On one hand, in a residential or nursing care setting, there is reason to believe that those family members who visit a resident are likely to do so on a regular basis or alternatively have privileged access to the resident, their finances or belongings (such as a spouse may have) or may otherwise have some active role in caring for a resident or managing a resident's affairs. It may therefore be reasonable to presume that the majority of family members visiting the home are in a fairly clear position of trust. On the other hand, restricting the definition of mistreatment to incidents involving staff and professionals clearly focuses the research on institutional mistreatment. Focusing on professional care relationships also avoids inadvertently including the inter-personal disputes and conflicts that can be part of all family relationships and avoids bringing together harms that are qualitatively different, have different causes and require different policy responses. However, a third approach may be preferable given the likely interest in incidents involving family members. This would be to have an inner circle of trust consisting of staff, volunteers and professionals and a separate surrounding circle consisting solely of family members. This would facilitate separate reporting of mistreatment by, on the one hand, institutional staff, volunteers and professionals and, on the other hand, family members.

We propose that there would then be an outer circle with other types of perpetrator such as friends, staffs' visitors, external workers (plumbers, electricians etc.). The reason these groups would belong in an outer circle would be that they are less likely to have specific responsibilities for the well-being of residents. Some friends may provide ongoing informal care or help to manage residents' affairs, and therefore belong in an inner circle of trust but we would not expect such individuals to be numerous. The perpetrators in this outer circle would be considered to be in a broad position of trust on the basis of the vulnerability of residents (in terms of care-dependency).

Diagram 1: Circles of trust



Setting out separate circles of trust provides a coherent approach that reflects the 'fuzziness' of the position of trust concept as it moves from those providing immediate care, through immediate family members and out towards those with less direct responsibility for the well-being of residents. It also presents the data in a disaggregated form by key groups of perpetrator – staff and relevant professionals, family members and others while allowing for estimates to be aggregated together where required. It also provides the flexibility to construct slightly different constitutions of perpetrators (for example, bringing staff, volunteers, professionals and family members together as a single group) and to present and compare alternative estimates based on different groups as was done in the secondary analysis study (Biggs et al., forthcoming).

Resident on resident and resident on staff incidents

We do propose that a prospective survey collect information about incidents which involve residents as perpetrators (resident-on-resident or resident-on-staff incidents). These reflect the level of conflict in a home and high levels of resident 'aggression' have been associated with high levels of reported abuse (Goergen, 2004). However, we do not think this should be called, or confused with, abuse and other mistreatment since the residents are not, by any of the definitions set out above, in a position of trust towards other residents or towards staff. We believe it would be confusing to refer to resident on resident or resident on staff incidents as occurring in a relationship involving trust or to

conceive of them as an abuse of that trust. An academic consulted as part of the stakeholder workshop conducted for this study argued against defining resident perpetrated harms as mistreatment, saying that:

'The term abuse is better reserved for situations where someone with greater power because of their role (whether as staff or a family caring role) abuses that power.'

Other consultees to the study, including Professor Catherine Hawes and Professor Thomas Goergen, believed that asking about resident on resident incidents would generate a large number of reports about inter-personal difficulties and conflicts which would be hard to get to the bottom of. As one consultee commented, *'When does two residents both wanting to sit in the same chair (one of whom sits there regularly) constitute bullying?'* Many of the residents will also be suffering cognitive difficulties that effect their behaviour, memory and emotional responses. Incidents involving aggressive resident behaviour towards staff may also be difficult to get to the bottom of. Such behaviour may reflect resident resistance to staff interventions that are unwelcome, confusing or which produce fear or anxiety. They may also be symptomatic of earlier failures to address emotional and behavioural issues. We do not under-estimate the potentially harmful impacts of resident-on-resident or resident-on-staff incidents such as aggression, assault or theft. However, if mistreatment is to be defined in relation to an idea of position of trust, implying recognised obligation towards someone in a less powerful position, we think that it would be unhelpful and confusing to refer to this behaviour as abuse or mistreatment.

Separately reported estimates of harms perpetrated by residents will provide a measure of the levels of conflict and inter-personal stress experienced by residents and staff and will allow comparison with other characteristics of mistreatment. Given that care homes have clear responsibilities to effectively manage conflict and behaviour within the home, we also think that it would be helpful to explore how staff and care home management act to manage resident on resident and resident on staff incidents and how they manage difficult behaviour from residents more generally, and we propose including questions which cover this.

Intentionality

Intentionality is a frequently debated aspect of definitions of elder mistreatment. Some conception of intentionality appears in a number of definitions of abuse. For example, the National Research Council (Bonnie and Wallace, 2003) defines mistreatment as:

'(a) intentional actions that cause harm or create a serious risk of harm (whether or not harm is intended) to a vulnerable elder.'

Professor Catherine Hawes, in her current development work for a prospective survey in the USA, plans to only cover intentional abuse and wilful

neglect rather than broader harms such as those arising from poor quality care. This work is still in development and the approach to asking survey questions to elicit this is as yet undeveloped. The WHO definition (2002), on the other hand, makes no mention of intent on the part of the perpetrator and instead focuses on the impact on the victim, defining mistreatment as '*acts ... which cause harm or distress to an older person*'. Following this definition, intent was not included as a parameter in the community survey. Certainly, it is difficult to know what a perpetrator's intentions were. Others, especially those representing service users, have argued that it should be the experience of the victim and not the intentions of a perpetrator which define whether an act is classed as abuse or other mistreatment. Whilst this rightly focuses attention on the victim's experience, it can lead to a relativist position and to holding practitioners to unclear or aspirational standards, such as ensuring residents 'have a sense of purpose in life' or 'feel needed'. A break-out group convened as part of the stakeholder workshop held for this study discussed this issue and concluded that, whilst it was important to understand residents' experiences and perceptions, there needed to be a balance of concern between the intentions of the perpetrator and the impact on the victim.

The report, *Rights, risks and restraints* (CSCI, 2007, p. 47), argues that '*it is essential to understand the complexity of the job of caring, the tensions in practice and the situations that care workers find difficult to manage. Over-simple and unrealistic assertions about the roles and responsibilities of staff must be avoided.*' It adds that '*care staff have an obligation to carry their work to a reasonable standard.*' The duty of care that care organisations and their staff have towards residents is set out in *Independence, Choice and Risk: A Guide to Best Practice in Supported Decision Making* (Department of Health, 2007). It states that '*an obligation [is] placed on an individual [staff member] such that they exercise a reasonable standard of care while doing something (or possibly omitting to do something) that could foreseeably harm others.*' We think that this concept of reasonableness appears a relevant one for guiding what should be included in a survey of mistreatment in residential or nursing care settings. We propose, therefore, that behaviours included within the overall definitions of abuse, neglect or loss of dignity should meet the criterion of the perpetrator 'knowing or being reasonably expected to know that an action or lack of action would or could cause harm to a resident'. It is intended that this be reflective of the 'reasonable standard' criterion described above. This criterion is not a prescriptive one and can be drawn more or less broadly. However, as a guiding principle, this criterion may help to focus the research on behaviours or experiences around which there is a broad consensus that they should, and could, reasonably have been avoided. Such a principle may also help to keep a clearer distinction between mistreatment and broader dissatisfactions, which many of our consultees believed was important if the findings were to be credible and if providers were to be willing to take part in the survey.

Age and risk of mistreatment

The community survey defined older person to mean someone who was aged 65 or over (respondents in the community survey were at least 66 years old in order to report 'in the past year' from age 65). Mowlam et al. (2007) and Dixon et al. (2009) gathered qualitative accounts of mistreatment from survey respondents who took part in the community survey to identify and explore age-specific factors related to the causes, experience or impacts of their mistreatment. They found that while some older people were in poor health or socially isolated, for example, many were not so, particularly in early older age. There was also not a direct relationship between these factors and vulnerability with, for example, older people in good health saying that they sometimes felt vulnerable because of assumptions other people might make about them not being able to stand up for themselves. Many of the factors considered to make older people vulnerable such as poor health or social isolation are also not unique to older people. Vulnerability therefore is better conceived of as situational or circumstantial rather than being an inherent characteristic of an individual (Penhale and Parker, 2008). The authors concluded that age itself does not make people more vulnerable to mistreatment and that there is not an age-specific form of mistreatment. This was confirmed by findings from the secondary analysis project (Biggs et al., forthcoming, p.67) which found that *'age dropped out as a risk factor when other factors were taken into account'* and similarly concluded that *'age in itself does not generate risk'*. As noted by Purdon et al. (2008), however, compared to the general population, residents in residential and nursing care will have considerably higher levels of ill-health and cognitive impairments, high levels of dependence on carers, often limited alternative options for care and, as intensive service-users, will also be highly vulnerable to service failures. These factors may mean that, relative to those in the community survey, respondents in a prospective survey of residential and nursing care settings are likely to be more 'at risk' to mistreatment.

We do not have views on whether an age criterion is set for inclusion in the survey sample, although we suppose most residential and nursing care facilities are unlikely to include residents across a younger age range. We do, however, encourage conceptual clarity in the way that the role of age is discussed when developing questions and reporting findings. Leroux and Petrunik (1990, p. 653) point out that frequently *'old age overrides all other statuses and has the most priority in the characterization of the individual'*. We recommend that, to avoid this, respondents should be referred to as 'residents' in reports rather than as 'older people' since this is more accurate (the sample is one of residents and will exclude older people who are not care home residents). It is also important to take care not to assume age itself causes vulnerability and thereby reinforce the ageist assumptions that can sometimes be found in discussions about elder mistreatment.

In order to move beyond broad and imprecise notions of age-related vulnerability to mistreatment, it will be important to use the survey to explore what risk factors are associated with mistreatment. Professor Catherine Hawes (2003, p.451), drawing upon findings from a range of previous studies conducted in residential and nursing care settings, identified the following victim characteristics as potential risk factors:

- dementia and cognitive impairments
- behavioural symptoms such as verbal or physical aggressiveness

Other victim characteristics that the Atlanta Long-Term Care Ombudsman Study (2000) suggests might be related to vulnerability to mistreatment include:

- incontinence
- need for higher levels of assistance with everyday tasks such as eating
- social isolation (i.e. no family or other regular visitors)

Other characteristics proposed by consultees to this study included:

- whether the resident is self-funding

Victim characteristics identified in the secondary analysis project as related to elder mistreatment included:

- sex
- marital status
- socio-economic classification
- depression
- quality of life
- regularly taking medicine.

Gathering good quality data on these factors will provide an opportunity to confirm to what degree they are associated with mistreatment, including loss of dignity, in a UK context. It will be also interesting to see what association there is between such risk factors and the different variants of mistreatment given that, in the secondary analysis of the community survey data, Biggs et al. (forthcoming, p.67) found that different forms of mistreatment are characterised by different risk factors.

However, we also believe that it is important to avoid an over-emphasis on victim characteristics. Such an emphasis was seen by some of those consulted for this study as problematising old age and construing the victim as somehow 'responsible' for their mistreatment. In fact, Biggs et al. (forthcoming, p.69) found evidence that, '*older victims do not attract more abuse, and forms of mistreatment may depend more upon perpetrator and contextual factors than victim characteristics*'. We therefore propose that as much information as feasible is also gathered about the perpetrator, the context of the mistreatment and the organisation within which the mistreatment occurred. We appreciate that there may be difficulties in gathering a full range of such information in a survey context. We discuss gathering information about the organisation in Chapter 7. Contextual information surrounding incidents will be harder to obtain through a survey. As noted by participants at the stakeholder workshop, understanding the series of events leading up to an incident is difficult in the context of a survey and qualitative research following up survey respondents is likely to be able to

provide far richer insights into the dynamics behind identified risk factors and point more clearly to policy action than prevalence figures alone.

Key points and recommendations: Trust, intentionality and age

- There is a consensus that mistreatment is defined as occurring within relationships involving trust. The concept of trust, however, remains vague and imprecise
- Position of trust is summarised as a recognised obligation or duty towards someone in a less powerful position. It was found to be a more transparent, robust and operationalisable concept than other more subjective notions of trust. It is highly relevant in an institutional setting and covers all forms of care-giving, the routines and practices within the care home and the maintenance and management of the care home environment
- Family members who provide informal care, manage a resident's affairs or finances or otherwise have privileged access to a resident and their belongings are in a position of trust. A familial relationship in itself is not sufficient. The vulnerability of residents on account of their care-dependency, however, suggests that all visitors to the home could be considered to be in a position of trust in a broader sense. We propose that 'circles of trust' based on these narrower and broader definitions of position of trust are used for reporting findings
- Incidents perpetrated by residents, towards other residents or staff, should be asked about and reported - they indicate the level of conflict in a home and resident 'aggression' has been found to be associated with higher levels of reported abuse. However, these should not be called, or confused with, abuse and should be reported separately
- The survey should reflect a balance of concern between perpetrators' intentions and the impact on residents. It should focus on incidents where the perpetrator knew, or could reasonably have been expected to know, that their action or inaction would, or could, cause harm
- Age in itself does not make an older person vulnerable. Care home residents, however, are likely to have much higher levels of ill-health and dependence than older people in the community. As intensive service users, they will also be more vulnerable to service failure
- When reporting, researchers should use the term 'residents' rather than 'older people' since the sample is one of residents and excludes older people not living in residential or nursing care
- While it is important to gather information about victim characteristics thought to be associated with mistreatment, researchers should also gather information about perpetrator characteristics, the context of

mistreatment and care home characteristics for a comprehensive and rounded consideration of risk factors

Chapter 4: Categories of mistreatment

Financial, psychological, physical and sexual abuse/ loss of dignity

The community study analysed results using five categories of mistreatment. These were financial, psychological, physical and sexual abuse, and also neglect. In a residential or nursing care setting the financial, psychological, physical and sexual abuse categories would appear to be broadly transferable. They also apply readily to definitions of loss of dignity since there is significant overlap between these and definitions of abuse and neglect, although also including a range of incidents involving less immediately serious harms. In a residential or nursing care setting, financial abuse may also contain somewhat different issues since residents are less likely to have full control over their affairs and finances than older people living in the community, depending on homes' policies, levels of cognitive impairment and the degree and nature of family involvement.

Neglect

The problems with a neglect category

The category of neglect is, however, more problematic. Hawes (2003, p.463) observes that, '*definitions of neglect are probably the most disputed of any category*' and Biggs et al. (forthcoming, p68) describe neglect as being an over-inclusive and under-specified category. The issue of inclusiveness is only increased in a residential or nursing care setting. As Purdon et al. (2008, p.19) point out in their feasibility study into transferring the community-based survey of mistreatment to residential or nursing care settings, '*the questions on neglect will have to be completely re-worked, as care home residents are on average much more dependent on help with everyday activities than older people living in the community.*' Extending the behavioural definitions to cover loss of dignity may also increase the number of forms of potential 'neglect'. Of the behaviours and experiences of mistreatment identified in the mapping exercise and set out in Chapter 2, all of the following reflect a failure to provide needed assistance or, following Hawes (2003, p.462) conducting a task inadequately (e.g. rough handling, conducting a one person transfer where a two person transfer is needed). The length and scope of this list makes it immediately apparent that a separate neglect category in a survey of residents living in care settings could easily become 'bloated' and unmanageable.

Finances

- Family acting to ensure that resident is given lower standard of care than needed or wanted in order to maintain assets for purposes of maximising inheritance

- Not being either rehabilitated or moved to higher support care because of financial incentives for institution in keeping older person in existing care setting
- Not having (sufficient) money of own for spending including being denied opportunity/ right to access personal funds
- Not being given appropriate assistance to manage/ monitor financial affairs (e.g. help reading bank statements)
- Not being given appropriate assistance to access benefits

Psychological abuse/ neglect

- Not using requested/ desired term of address/ using overly informal or familiar terms of address
- Excluding resident or repeatedly ignoring them (e.g. 'silent treatment')
- Failing to ensure adequate level of socialisation/ inter-personal engagement
- Lack of appropriate communication methods with those with people with sensory impairments or dementia (e.g. visual aids, non-verbal communication)
- Lack of engagement with wider community/ Lack of assistance to travel outside care-home
- Lack of enhanced support at times of acute distress in a manner that takes account of resident's preferences
- Not talking, interacting while delivering care
- Staff forgetting when family and friends are due to visit and do not ensure appropriate arrangements
- Lack of reminiscence activity for dementia sufferers
- No or few activities for residents; lack of stimulation
- Not identifying/ using older person's skills, abilities
- Residents not permitted to participate in/ contribute to day to day running of the home
- Not respecting individual choices about own care
- Not supporting residents to make decisions where needed, including those with cognitive or communication difficulties
- No choice in décor or furnishing of own room
- Lack of choice concerning appearance (e.g. dress/ hair)
- Not wearing own clothing
- Not having own glasses, hearing aids, dentures
- Lack of choice concerning schedule
- Lack of maintenance of respectable appearance
- Lack of sensitivity and responsiveness to culture, religion, age, disability, gender and sexuality
- Being denied food or privileges as punishment
- Failure to provide adequate explanation and information, in appropriate format, free of jargon

Privacy

- Lack of privacy in personal space (bedrooms, bathrooms and toilets/ commodes) or for the giving of personal care
- Lack of single sex or en suite toilets/ bathrooms
- Staff and others not knocking/requesting permission before entering private space
- Lack of privacy for medical consultation with, and examination by, health professionals
- Lack of privacy for consultations with legal and financial advisors/ social workers
- Lack of privacy for expressions of intimacy and sexuality (with appropriate assessment of risk to vulnerable people)
- Lack of privacy in communications - when meeting with friends and relatives, mail being opened by others, not receiving mail promptly, no private use of telephone
- Lack of ability to spend time alone when wanted
- Lack of privacy of care received prior to and at time of death
- Lack of confidentiality/privacy of personal information
- Overcrowded conditions

Physical abuse/ neglect

- Being handled roughly during giving of care
- Ignoring calls/ requests for assistance/ call button
- One rather than two person transfers
- Lack of appealing, good quality food; poor nutrition
- Lack of availability of food/ snacks between meals
- Lack of appropriate and dignified assistance to eat food/ drink
- Lack of freely available and accessible drinking water
- Failure to address significant weight loss (e.g. measuring food and fluid intake)
- Lack of consultation on menus with residents; taking account of individual preferences
- Lack of clean, tidy environment free from unpleasant odours
- Environment not adapted to needs of residents (e.g. those with mobility impairments)
- Not being given needed medication/ medical attention (including hearing aids, glasses and prostheses and oral/ dental care)
- Being given insufficient information about medication
- Attending medical appointments without staff ensuring relevant information/ paperwork or bringing residents at the wrong time
- Lack of adequate pain control
- Staff forget when professionals are due to visit and do not ensure appropriate arrangements
- Failure to gain professional advice for behaviour such as extreme distress, anxiety, aggression
- Failure to take action to prevent bed/ pressure sores
- Is not appropriately dressed – too hot or cold

- Insufficient exercise/ not doing 'range of motion' exercises
- Residents not supported to have good personal hygiene
- Leaving residents in the toilet, on a commode for an extended period of time

Other

- Lack of systems available for complaining about services that residents are aware of and know how to access
- Lack of support to access complaint system if needed
- Complaints not appropriately and promptly handled.

Related to this problem of inclusiveness, is that neglect effectively cross-cuts the different areas covered by the abuse categories, particularly physical and psychological. This can mean that a group of items relating to the same area of care are unhelpfully fragmented across neglect and an abuse category. For example, nutrition covers failure to provide sufficient help with eating, failure to address severe weight loss and failure to provide appetising food (neglect) as well as withholding of food as punishment and rushing residents to eat or interrupting mealtimes (physical abuse). In practice, these behaviours could probably all be re-conceived as neglect; as a failure to ensure adequate nutrition. This, however, points to a further difficulty which is that the distinction between neglect and abuse can be rather 'fuzzy'. Withholding food as punishment, for example, involves an absence of positive action so could be considered neglectful. However, the deliberate intent to withhold the food and to harm suggests that it is maybe best viewed as abuse, and this seems a more intuitively appropriate way of classifying the behaviour. But what about not responding to a call light because, in the view of the staff member, a resident has called for assistance an excessive number of times for minor things? Does that constitute neglect or abuse? Intent to ignore the call light is there but not the intent to harm, although harm may befall the resident as a result of having a call ignored. Intuitively this appears to be more an act of neglect. However, the distinction lies only in the intent to cause harm. A further complication with the category of neglect is that, particularly in an organisational setting, it can be inter-related with incidents of abuse. For example, inappropriate restraint or medication may result from a previous failure to effectively address emotional or behavioural problems.

Approaches for categorising neglect

The problems of imprecision and over-inclusiveness associated with neglect are significantly increased in residential and nursing care settings because residents are highly dependent on care and assistance with everyday activities, as well as medical care, and consequently vulnerable to a wider range of neglectful behaviours. However, given the greater potential for neglect in a care home, it being indicative of poor levels of care and its potentially significant impact on resident's well-being, we do not recommend abandoning the category.

One approach would be to ask about the wide range of different possible acts of neglect individually. This would give the most specific and precise data since respondents would be asked highly specific questions with less room for subjective assessment. However, in practice, it will not be possible to ask individually about each possible act of neglect given the very wide range of potential acts of neglect that could occur in an institutional setting. Whilst it is no doubt possible to identify a more limited list of key neglectful behaviours than those listed above, it seems unlikely that this could be reduced to a number of items sufficiently small for it to be feasible to ask questions about individual acts.

A more manageable approach may be to identify more general questions about particular areas of care. This is broadly the approach used in the community survey. Given the increased number of potential acts of neglect in a residential and nursing care, however, it will be especially important to ensure that the areas of care identified and asked about are robust, coherent and transparent and do not bundle too many diverse behaviours together.

We think that the first step in developing such an approach is to identify a more manageable number of key neglectful behaviours and experiences. These would:

- provide a basis upon which to identify broad areas of care around which to construct questions
- be used as specific examples to support respondents when answering questions

There is no clear agreement on what might constitute key acts of neglect in a care home setting. However, two studies in particular provide a basis for a reasonably robust list of behaviours that meet the 'reasonableness' criterion we proposed earlier; the perpetrator knowing or reasonably being expected to know that their action or lack of action would or could cause harm. One of these is a study conducted by Professor Catherine Hawes (2003) in which she interviewed staff working in care facilities in the USA. The staff that she interviewed identified the following acts of neglect:

- not changing after incontinence or soiling
- not giving regular baths
- not scheduling toileting or helping residents to the toilet when asked
- ignoring a call light/ alarm
- not conducting range of motion exercises
- not keeping residents hydrated by providing water and/or prompting those with cognitive impairments to drink
- not providing oral/ dental care
- not offering activities to/ ignoring the bed-fast

The staff interviewed also identified not doing prescribed wound care, not cuing or providing task segmentation to sustain independence and carrying out a one-person rather than two-person transfer but these were thought less

appropriate to ask directly of residents or their representatives. Potentially, however, they could be asked of staff.

The Atlanta Long-Term Care Ombudsman Study (2000) drew on primarily qualitative interviews with a convenience sample of care facility residents identified by local ombudsmen. This study further identified the following acts of neglect:

- not re-positioning/ turning residents to avoid pressure sores/ ulcers
- not providing enough assistance at mealtimes leading to poor and malnutrition

Consultation and discussions carried out as part of this study suggest that the list could also reasonably include the following behaviours, identified from the mapping exercise:

- insufficient pain control
- lack of appropriate communication methods with those with people with sensory impairments or dementia (e.g. visual aids, non-verbal communication)
- not respecting individual choices about care, not supporting residents to make decisions where needed
- lack of social interaction/ activities (to all residents, in addition to the bed-fast mentioned by Hawes' respondents)
- not addressing significant weight loss
- being handled roughly during giving of care (a more general behaviour related to the two person rather than one person transfer referred to in the Hawes study)

Privacy is not covered in the above lists but is a distinct area of neglect and a highly important aspect of dignity in care. Residents in residential and nursing care homes receive high levels of personal care in close proximity to other residents, living what Peace et al. (1987) refer to as '*private lives in public places*'. Consequently it will undoubtedly be important to be able to analyse and report on privacy separately. Commonly behaviours relating to privacy appear to be forms of neglect; that is failing to carry out care in a way that maintains appropriate privacy (e.g. performing intimate care without closing the door or erecting a screen). However, some may be active behaviours such as opening residents' mail or bathing several people at the same time although, in order to keep all the behaviours relating to privacy together, we suggest that these are conceived of as failures to ensure privacy and that they are measured together. Relevant behaviours identified from the mapping exercise might include:

- leaving people on a toilet or commode for extended period of time
- lack of privacy in personal space (bedrooms, bathrooms and toilets/ commodes) and/or for personal care
- lack of privacy for medical consultation or examination by health professionals
- not being able to spend time alone when wanted

- lack of confidentiality/privacy of personal information
- lack of privacy in personal communications (e.g. no-where private to go to speak to family and friends)

This list of neglectful behaviours covers a wide range of areas of care and different dimensions (physical, psychological and loss of dignity), the behaviours meet the reasonableness criterion discussed earlier and, although there is unlikely to be a consensus about exactly what behaviours should be included, it appears to represent a robust selection of neglectful behaviours with no obvious or glaring omissions. However, the list is suggestive rather than definitive, with the selection based broadly on views expressed during consultation events and developed through team discussions. Further development work may be needed to clarify and possibly refine the list.

By grouping together these behaviours, it is possible to develop a set of intuitively understandable areas of care around which questions can be constructed. We provisionally suggest the following areas of care although these will require further consideration during a process of questionnaire and question development, testing and piloting. These cover failure to provide needed assistance, inadequate assistance and lack of privacy.

Failure to provide assistance (where needed)

The questions covering failure to provide needed assistance could, we think, take the following broad form:

- Have you needed help with [area of care] in the last [time period]?
- By help with [area of care] we mean things like [give examples]
- (If yes) has there been a time in the last [period of time] when you needed help with [area of care] and did not receive it or had to wait much longer than you think was reasonable?

This would need further testing and development particularly around issues such as how easy it was for respondents to remember the examples when answering and the periods of time that respondents thought constituted 'waiting much longer than you think was reasonable'. A decision needs to be made as to whether to ask respondents solely about the example behaviours or whether to invite them to include 'similar' behaviours. If the latter, it will be important to test what sort of similar needs respondents include when answering.

The areas to be covered and the examples would, we suggest, cover the following:

- **Toileting:**
 - being changed after incontinence or soiling
 - being taken to the toilet regularly or when you ask
 - helping you back to bed/ bedroom/ lounge after using toilet/ commode

- **Personal care and hygiene:**
 - helping you wash/ take regular baths
 - helping with oral/ dental care
- **Hydration and nutrition:**
 - being given assistance to eat at mealtimes
 - being given water to drink regularly/ being helped to drink enough water
 - if you have lost a lot of weight, staff trying to find out why and helping you put weight back on
- **Social:**
 - helping you to interact socially with others (e.g. through organised social activities such as games or singing or volunteers coming to chat to you)
- **Communications:**
 - if you have sensory impairments or dementia, getting help to communicate effectively with others (e.g. visual aids, non-verbal communication)
- **General**
 - responding to you when you press the call alarm/ light
 - responding to you when you call out or ask for help

Inadequate assistance

The proposed questions covering inadequate assistance would, we suggest, include:

- **Handling**
 - In the [time period] have you been handled roughly while being given care? By roughly we mean in a way that caused you more pain/ discomfort than you think was necessary?
- **Medical care**
 - (for bed-fast) Do staff move you regularly enough to avoid pressure sores/ ulcers?
 - Was there a time in the last [period of time] when you were not given sufficient pain control? By this we mean that you were in much more pain that was necessary.
 - On the whole, do you think that your choices about you care are respected?

The construction of the questions, and any accompanying clarifiers or explanations, around medical care will need to draw upon testing that explores methods of asking these questions so that respondents are able to answer them in a relatively consistent way.

Lack of privacy

We propose questions of the following form to cover privacy issues.

- When being given assistance with/ engaging in the following activities in the last [time period] was there any time when this was not private enough? By not private enough we mean that other people saw or heard things that you thought should have been/ wanted to be private to you or private between you and whoever was helping you at that time.
 - Getting a bath
 - Going to the toilet/ using a commode
 - Eating (if you have problems/ need help eating)
 - Medical consultation/ examination
 - Personal conversations with family and friends
- Are you able to be somewhere to spend time alone when you want?

This broad suggested approach to managing the large number of neglect behaviours that may occur in residential and nursing care settings is designed to balance the needs for specificity, coverage and manageability. It is not meant to be prescriptive but we hope that it can provide a helpful point of departure for further development. As with all survey questions, these questions will need to be adapted if they are to be asked of proxy or alternative respondents.

Identifying perpetrators in the case of neglect

A further issue that will need to be thought through is that, unlike with acts of abuse, it will be difficult to identify a perpetrator/or perpetrators since the neglect will have taken place in a context where there are multiple care-givers and in which it is not likely to be clear who should have responded to the residents' need(s) (Goergen, personal interview conducted for this study). Furthermore, organisational factors may play a more direct role in neglect. For example, under staffing could make it more likely that residents' call lights or alarms are ignored and, in such cases, it is possible that there is no readily identifiable individual who failed to provide this assistance but that the failure was systemic and more properly viewed as an organisational failure. The relevance of the organisational level is discussed further in Chapter 7.

Consultation and redress

Finally, in an institutional setting, the role of consultation and engagement with service users and relatives and the availability of adequate redress for alleged incidents of abuse, neglect and loss of dignity should be of special interest

and appears to require survey coverage and a separate category.

Key points and recommendations: Categories of mistreatment

- With minor adaptations, the financial, psychological, physical and sexual abuse categories used in the community survey are transferable to a care home setting and can cover loss of dignity. Neglect remains a problematic category; tending to be over-inclusive and hard to distinguish from abuse
- It will not be feasible to ask about individual acts of neglect given the potentially large number of these in a care home setting. A preferred approach is to ask general questions about key areas of care making reference to specific examples. We make proposals for questions covering toileting; personal care and hygiene; hydration and nutrition; socialising; communications; medical care; physical handling; privacy and requests for assistance
- It is difficult to identify perpetrators of neglect in a care home setting since it will often be unclear who should have provided the assistance and organisational factors may also play a direct role in failures to provide aspects of service adequately or at all
- Consultation and engagement with service users and relatives and adequate redress for alleged incidents of abuse, neglect and loss of dignity will be of special interest and requires a separate category

Chapter 5: Subjectivities, qualifiers and thresholds

Subjectivities

Potentially over-inclusive behavioural definitions

The lack of clear definitions in this area can lead to survey questions that are imprecise, over inclusive and which capture behaviours outside of those intended. For example, Mowlam et al (2007) and Dixon et al (2009) identified problems with the over inclusivity of some of the behavioural definitions used in the community survey, particularly in relation to psychological abuse. In the community survey, respondents were asked if anyone had repeatedly (ten or more instances) insulted them, called them names, sworn at them, threatened them, undermined or belittled what they do, excluded them or repeatedly ignored them. They were also asked if anyone had (on any one occasion) grabbed, pushed or shoved them. The qualitative research that followed up respondents to the community survey found that some respondents interpreted these sorts of questions in ways that captured a wide range of inter-personal and substantive disputes that did not seem to involve any abuse of position of trust or power. It also found that some cases of neglect appeared to reflect service failure rather than one-on-one incidents. Inclusivity has been a long-standing problem with definitions of elder mistreatment and the problem of questions being widely interpreted could be exacerbated in a survey extended to cover loss of dignity, including as it does a range of less immediately serious harms and behaviours.

Focusing on professional relationships involving position of trust should help to remove some of the ambiguity around such questions as it seems likely that these behaviours would always be inappropriate in these relationships. They are likely to also be inappropriate where a resident is particularly 'vulnerable' due to dementia, for example. The prevalence of position of trust relationships and levels of dependence and vulnerability in the context of care settings therefore may mean that problems of over-inclusive behavioural definitions are lessened. However, in inter-personal relationships with family and friends, there will remain a line between normal expressions of conflict and behaviour that constitutes abuse. Where exactly this line lies is likely to be based upon factors such as whether the behaviour constitutes an abuse of position of trust or power and the severity of the behaviour/ perceived impact on the victim. For incidents occurring in these relationships, a tighter definition of the sorts of behaviours that are being asked about may be helpful, respondents may need to be reminded about the importance of frequency thresholds where these are used. In addition, a qualifier reflecting severity could also be introduced where appropriate which alongside a frequency threshold could provide a measure of what we might refer to as 'density'.

Variation in how key terms are understood

In some cases, individuals may apply different understandings of the same concepts and terms. The research and consultation conducted for this study, for example, suggested that privacy may be a term around which there are variable interpretations. In one of the resident interviews conducted for this study, a resident's husband interpreted privacy to mean peace and quiet. Professor Catherine Hawes found, in the qualitative interviews that she conducted with residents in care facilities in the US, that asking about lack of privacy in the poorer care facilities tended to elicit accounts of inappropriate public nudity whilst in better facilities residents claimed to have a lack of privacy because there were so many social activities that they did not have enough time for themselves (personal interview conducted for this study). These findings clearly suggest that appropriate clarification of what is meant by the idea of privacy needs to be given. It also demonstrates that a respondent can give apparently valid answers to questions but have failed to understand a key term in the way intended by the researchers; particularly in the case of more abstract concepts. This places importance on rigorous question development and testing to identify terms that may not be consistently understood. There is also a need to be alert to the fact that there are many abstract terms involved in defining abuse, neglect and loss of dignity. It may not always be immediately apparent that a concept is an abstract one and, consequently, subject to different conceptions and understandings.

Researching subjective feelings

In the consultative events, a view was expressed that it could be important to know how many people *feel* they have been abused. This is certainly a valid point of view and one which places emphasis on eliciting older people's own perspectives on their experiences. The dignity in care agenda, in particular, places considerable emphasis on people's own subjective experiences. The Dignity in Care campaign run by the Department of Health, for example, outlines a set of responses to mistreatment that are seen to be markers of loss of dignity, and in particular loss of what Tadd (2004) refers to as '*dignity of identity*'. Examples of the kinds of behaviours that might elicit these responses are provided in some cases:

- feeling neglected or ignored whilst receiving care
- being made to feel worthless or a nuisance
- being treated more as an object than a person
- feeling their privacy was not being respected during intimate care (e.g. being forced to use a commode in hospital rather than being provided with a wheelchair and supported to use the bathroom)
- a disrespectful attitude from staff or being addressed in ways they find disrespectful (e.g. by first names)
- generally being rushed and not listened to.

The list also includes two items that are not descriptions of impact or subjective experience but are descriptions of concrete behaviours.

- being provided with bibs intended for babies rather than a napkin whilst being helped to eat
- having to eat with their fingers rather than being helped to eat with a knife and fork

Whilst these definitions may provide a good 'feel' for what is meant by loss of dignity, they are not precise enough to function as research definitions and they confuse abusive or neglectful behaviours with the way in which they are perceived and experienced. It is certainly possible to ask residents whether they have experienced something that caused them '*to feel worthless or a nuisance*' and estimates of prevalence can be produced. However, these figures will be difficult to interpret and are likely to lack credibility since '*being made to feel worthless or a nuisance*' can arise from experiences that we may classify as abuse or neglect as well as a wide range of more minor problems and difficulties.

There are a range of underlying reasons for variability of this sort. People can simply respond differently to the same experience (or similarly to different experiences). Terms used to describe subjective experiences are abstract and difficult to standardise; hence '*feeling worthless*' stands for an unobservable internal state and is subject to varying interpretations. People may, therefore, differently ascribe 'labels' to their responses. For example, my feeling worthless may only correspond approximately to your idea of feeling worthless. Respondents may also downplay or excuse behaviours because they feel sorry for staff who they perceive to be under pressure, may have low expectations or because they have adjusted their expectations in the light of ongoing poor care, may not be sure what level of care is acceptable or may defer to the 'expert' views of professionals and staff. They might alternatively be fearful of complaining for fear of reprisal and/or because they have no, or few, alternatives for otherwise receiving the care they need. Professor Thomas Goergen (personal interview conducted for this study) said that in his research he found that residents had modest expectations and made few complaints, probably fewer than providers expected, and he thought that this could have possibly been because of these sorts of reasons. On the other hand, other consultees to this study thought that residents may also sometimes experience negative feelings in response to an apparently less serious experience because they are unhappy about their circumstances more generally. This may be for a wide array of reasons associated with, but not necessarily because of, living in residential or nursing care including, such as coping with loss of independence, loss of social connections, bereavement, isolation, lack of emotional intimacy or affectionate touch, loss of a sense of purpose, lowered self-esteem, loss of cognitive capacity, illness, depression and nearness to death. Whilst it is important that distress and depression are appropriately addressed, it may not be reasonable to expect care staff to alleviate all such difficult feelings. Finally, there are also issues of attributability; a respondent, for example, may have been more prone to feeling worthless before an experience of mistreatment because of other difficulties.

For these reasons, a survey is generally not the best way of researching people's subjective responses. If an estimate of prevalence about subjective responses is required then we suggest information about this is gathered separately but alongside questions about the concrete behaviours and experiences underlying these so that they can be placed in context. Asking about respondents' perceptions in addition to questions about actual behaviours or experiences will place additional pressure on limited questionnaire space and interview time. We believe that, in many cases, it is self-evident that particular behaviours/ experiences are harmful and demeaning and are not sure, in these cases, that interview time and survey resources should be devoted to confirming this. Some information about people's subjective experiences may, however, be useful and at an aggregate level, correlations between high levels of negative subjective experiences and other factors may highlight useful areas for further analysis. We therefore propose that questions about subjective perceptions and responses are asked, interview time allowing, but kept to a number of key questions where these clearly add value. We believe that more extensive exploration of respondents' perceptions and subjective experiences are more appropriately explored through qualitative research.

Qualifiers

In mapping definitions and descriptions of abuse, neglect and loss of dignity, we found extensive use of qualifiers such as 'excessive', 'inappropriate', 'unwarranted' and 'unnecessary'. These reflect the fact that mistreatment in the context of residential and nursing care will frequently relate to a behaviour which is routine or can be legitimate but which is inappropriate in a particular instance or has been inappropriately carried out. Sometimes the behaviours may relate to some inappropriate way in which routine care was delivered; for example, being moved a rough manner. In other cases the behaviour itself will be legitimate on far fewer occasions although it potentially could be. For example, The Care Standards Act 2000 states that restraint should be used when it is the *'only practicable means of securing the welfare of that or any other service user and there are exceptional circumstances'*. The Mental Capacity Act 2005 states that, *'restraint may only be used where it is necessary to protect the person from harm and is proportionate to the risk of harm.'* It also requires that restraint is applied using minimum force for shortest possible time. The Mental Health Act 2007 goes on to introduce specific deprivation of liberty safeguards. Professor Thomas Goergen (personal interview conducted for this study) argued that these forms of mistreatment were particularly challenging to ask about in a way that was reliable since they depended heavily on context and required a subjective judgement from the respondent (about whether the action was or was not appropriate, excessive, unnecessary etc.). People will use a range of different reference points to reach this subjective judgement. Reaching a judgement may also call for technical or specialist knowledge that the respondent may not have.

A further complication is that some terms may not at first appear to be qualifiers but effectively act as qualifiers. For example, the term 'roughly' as in 'handled roughly' acts as a qualifier, since the fact of handling is not at question but rather whether it was or was not 'roughly' carried out. Various factors may influence people's judgements about whether they were roughly handled. For example, in our interviews with residents we were told that those who are in more pain or experiencing tenderness, as well as those who are larger and harder to move, may be more likely to experience the same handling as 'rough'.

Given that a significant amount of mistreatment in residential and nursing care settings is likely to involve behaviours that are routine or legitimate unless inappropriately carried out, qualifiers cannot be avoided altogether. However in order to increase the reliability of responses, it will be important to be alert to terms that act as qualifiers and to provide guidance to the respondent on how to interpret these terms. For example, a question about rough handling may require the additional information, *'by roughly we mean in a way that caused you discomfort or pain that you think could have been avoided'*.

Thresholds

Frequency thresholds (commonly of 10 incidents or more in last 12 months) were applied in the community survey to distinguish abuse and neglect from other less serious, one-off incidents while, at the same time, recognising the cumulative effects of repeated low level harms. In the secondary analysis project (Biggs et al., forthcoming), estimates using these thresholds were compared with estimates based on incidents that occurred one or more times. Where thresholds are set will naturally affect overall prevalence figures and the composition of incidents included. The secondary analysis study found that the impact of removing frequency thresholds was to increase overall prevalence and to expand the relative number of incidents perpetrated by neighbours and family members other than spouses. However, as Biggs et al. (2009, p.65) note, expanding the definitions used in the community survey by removing any thresholds *'runs the risk of grouping together phenomena that may otherwise have little in common'*.

Frequency thresholds are concrete and quantifiable and are therefore more likely to generate reliable and consistent answers than the alternative of using qualifiers or measures of subjective impact and are useful for identifying those experiences where a pattern of behaviour is indicative of mistreatment. For example, a single missed bath or meal may be an unfortunate oversight or a reflection of an exceptional circumstance. However, a pattern of missed meals or baths suggests mistreatment and poor care likely to result in physical and psychological harm to the resident.

Professor Thomas Goergen (personal interview conducted for this study) says that frequency thresholds imply a standard or 'comparison criteria'. However, since in practice there usually is no clear and objective external standard, where they are set can appear arbitrary. We expect, however, that frequency thresholds will continue to have a role in a survey of residents living in

residential or nursing care since one-off, more dramatic incidents of mistreatment are relatively rare compared to a range of less serious behaviours where there may be a need to identify a pattern to define them as mistreatment. Such behaviours may also be qualitatively different from those where one instance is sufficient to constitute mistreatment, perhaps reflecting overall poor levels of care rather than specific and distinct incidents of mistreatment. For example, *Raising Voices* (CSCI, 2008) points out that abuse procedures may be more relevant for those acts that require just one act to be defined as abusive or neglectful. These may also be more likely to be criminal as well as abusive acts. *Raising Voices* argues that where there are numerous but less immediately serious incidents this may be more suggestive of poor care standards and the need for organisational level remedies such as improved staff training or increased staff levels.

Key points and recommendations: Subjectivities, qualifiers and thresholds

- A lack of clear definitions can lead to the inclusion of inter-personal conflicts and substantive disputes. Focusing on professional relationships involving position of trust may remove ambiguity since behaviours such as swearing, insulting, belittling or pushing will always be inappropriate in these relationships. However, these behaviours may reflect 'normal' expressions of conflict in personal relationships. Respondents may need reminding of frequency thresholds and qualifiers could be additionally included alongside thresholds to provide a measure of 'density'.
- Individuals may appear to give valid answers to questions but understand the same terms differently. Privacy, for example, was found to be subject to different interpretations. Care needs to be taken to clearly define all abstract concepts in highly concrete terms
- A view was expressed that it was important to know how many people *feel* they have been abused and the dignity agenda, in particular, places considerable emphasis on subjective responses and impact. However, behaviours defined in terms of their subjective impact (e.g. '*being made to feel worthless or a nuisance*') can confuse concrete behaviours and the subjective reactions to them. Questions about subjective responses should be asked separately to questions about behaviours
- Responses about subjective impact can be difficult to interpret and factors such as existing problems, low expectations and fear of reprisal can influence how people assess their experiences. Survey questions about subjective impact should only be included where their value is clear. More extensive exploration may be undertaken using qualitative methods
- Qualifiers such as 'excessive' or 'unnecessary' are needed to define abusive behaviours that are routine or legitimate when carried out appropriately but can require respondents to make subjective judgements and may require specialist knowledge. Some terms such as '*roughly*' as in

'handled roughly' may not appear to be qualifiers at first but effectively act as qualifiers. To maximise consistency of interpretation, survey questions should provide further guidance to residents in the form, *'by excessive we mean ...'*

- Frequency thresholds exclude one-off, less serious incidents whilst at the same time recognising the cumulative effects of repeated low level harms. They are concrete and quantifiable although where they are set can appear arbitrary. They will continue to have an important role in a survey of abuse, neglect and loss of dignity in care home settings.
- Acts that require just one act to be defined as mistreatment may be more likely to merit abuse or criminal procedures. Numerous but less immediately serious incidents are more likely to suggest organisational failings and poor care standards and the need for organisational remedies such as improved staff training or increased staff levels.

Chapter 6: Length, scope and answerability

Length of interview

Qualitative interviews conducted with care home residents and family members for this study sought views on what constituted a manageable length of interview with care home residents. Estimates provided ranged from 15 minutes to a maximum of 35-40 minutes. It was thought that this depended on how unwell or frail the resident was and whether the resident was in more or less pain at the time of the interview; in the words of one resident, whether or not it was a *'good day'*. It was thought that few residents would be able to sustain an interview at the upper limit of 35-40 minutes.

Experience of conducting these interviews suggested that interviews could also be slow and it could take a long time to cover a small number of questions. Professor Catherine Hawes (personal interview conducted for this study) confirmed a similar experience in interviewing cognitively able, but nonetheless frail, residents in care facilities in the USA. This can place significant restrictions on the length and scope of an interview.

Purdon et al. (2008) also point to the need for introductory questions to be used for screening for cognitive impairment. From an ethical perspective an interview also needs to be 'closed down' with more general questions so that the respondent is guided away from concerns about mistreatment and poor care to more neutral topics before the interview is ended. These introductory and closing questions can be used to gather demographic data and to seek more general views but is still likely to take up time that could otherwise be devoted to directly exploring incidents of mistreatment.

In interviews conducted with residents for this study, residents occasionally gave apparently valid answers while not fully understanding the question but rather having taken an associated meaning. This may suggest that validation questions, to ensure that residents have understood the questions they have been asked and that they are providing consistent answers, would be helpful. However, this would place a significant additional burden on interview length.

As has been noted already, the breadth and scope of existing definitions and descriptions is considerable. There is no existing knowledge about how these items co-vary and no indication that asking about some areas in any way represents or stands for other related areas. For example, there are a wide range of potential questions that could be asked about nutrition but we do not know which may be the most important or indicative to ask about. In some cases, a series of related questions may also be useful to provide more detailed exploration of an issue or where a behaviour is particularly multi-faceted. For example, restraint covers a wide array of different behaviours. Stones identifies these as covering physical, chemical, environmental and medical restraint along with electronic surveillance and, as noted in *Rights, risks and restraints* (CSCI, 2007), this can include anything from being

strapped down to the strategic placing of small items of furniture to prevent free movement. There may also need to be separate questions about actual behaviours and subjective responses to that behaviour (as discussed in Chapter 5). This all points to a need to heavily focus the interview with residents on issues of key interest and to accepting that all aspects of abuse, neglect and loss of dignity cannot feasibly be covered in a resident interview.

Scope

If the survey is to adequately reflect the concepts of abuse, neglect and loss of dignity it will need to include a representative range of relevant behaviours. An active effort should be made to ensure that the survey covers experiences across a range of mistreatment covering abuse, neglect and loss of dignity and various areas of care and activity. It should also include behaviours and experiences of varying levels of seriousness and severity. As already noted, serious abuse is likely to be rare and difficult to detect. Less serious incidents will be more common and can have significantly harmful effects on older people's well-being, especially where these are repeated or prolonged. However, the disproportionate inclusion of a lot of low-level incidents increases the potential for the problems with over-inclusivity, subjectivities and thresholds discussed earlier and could open the findings to criticism for not distinguishing between mistreatment and broader difficulties and dissatisfactions. A provider representative at the stakeholder event held for this study argued that if a wide range of low level issues were to be included then overall prevalence rates may suggest higher levels of abuse, neglect and loss of dignity than might be accurate or fair. As a result, he believed that care homes may be reluctant to take part. It is important, therefore, that an appropriate balance is arrived at.

It will also be important, when developing and piloting the questionnaire, to test content against the concerns of residents themselves. For example, in the interviews with residents conducted for this study, residents had different views on the importance of some areas of privacy. For example, bed-ridden residents liked to have their doors ajar so they could see people come and go. Given that doors were ajar some residents said that staff rarely knocked before coming in. One resident pointed out that even if staff came in without knocking when the door was closed he did not mind at all as he could hardly move and was dependent on staff for all intimate care so thought himself highly unlikely to be interrupted doing anything he considered private. This resident said the staff, perhaps because they knew about his preferences, only knocked if the door was closed while his wife was there. This was, he thought, in order to ensure her privacy and his privacy should his wife be providing care to him. On the other hand, all residents agreed that any intimate care should always be given behind a screen and/or with the door closed and agreed that this was always done. As Leroux and Petrunik (1990 p. 661) point out there is the possibility that there are two distinct sets of problems with regard to the mistreatment and undignified treatment of older people *"those that older people actually have and those that experts think they have"*, a possibility that requires careful consideration in the selection of topic areas

and survey measures for a prospective survey of abuse, neglect and loss of dignity in residential and nursing care.

Finally, it may in practice be necessary to select a relatively small number of behaviours and experiences around which to attempt to gain an estimate based on residents' responses compared to the wide range of areas that could be included. This may be the only feasible way of making resident interviews manageable. Unfortunately there is no short-cut to selecting the most relevant areas. While there exists no ultimate list of core measures that should be covered, we believe that the reasonableness criterion of the perpetrator knowing, or being reasonably expected to know, that their action or inaction would cause harm discussed earlier can help guide selection, that the measures will need to represent a spread across different areas of care and aspects of mistreatment and that questions should be those that residents are most able to provide accurate and robust answers to. We would expect these core measures to reflect those behaviours which most people would view as unambiguously constituting mistreatment; the 'standard cases' discussed by Dworkin. We believe that a nationally representative survey of residents about their experiences of mistreatment for even a sub-set of possible relevant measures, provided these are seen to clearly represent the concepts being measured and are based on carefully developed and robust questions, is potentially hugely valuable.

Answerability

Findings from the research and consultation conducted for this study emphasise the challenges and difficulties of gaining full and accurate information, particularly for those residents that are unable to participate directly in a survey interview.

Residents

In care settings, residents may have cognitive difficulties of different severity and may be ill or frail. For those with cognitive impairments or too ill to take part in a survey, Purdon et al. (2008) proposes, and discusses at length, the use of alternative respondents such as other residents, family members, other visitors and staff.

For those residents who are interviewed directly, there will be a number of factors potentially affecting their ability to answer survey questions. Time periods and frequency recall may be challenging for those living in a situation where time is relatively unstructured and where one day may be much like any other. In situations of this sort it would be usual to use markers to help anchor people's recall to other events. However, it is difficult to think of a marker other than Christmas that most residents would be likely to be aware of and remember. Provision will also need to be made for the fact that residents will have been living in the home for various periods of time, and many may not have been living in the home for as long as 12 months. These findings reflect those of Purdon et al. (2008, p.11) who report that, '*the*

interviewers felt that respondents were unable to focus on the relevant time period ... the interviewers formed the impression that most respondents ignored recall periods'.

Residents may also not have the relevant knowledge to answer some questions. For example, if they are taking various medications, they may not know or remember what they all are and what they are administered for. They may not, therefore, be aware of being given medicine to manage their behaviour or 'keep them docile'. In interviews with residents conducted for this study, residents were divided between those who felt they would know if they had been given 'too much' medication and those who seemed less clear. However, some also said if they were told they needed to take more or different medication by a nurse then they would presume this was needed for medical reasons and would not think it was to keep them docile.

However, notwithstanding these potential problems, Purdon et al. (2008), in their feasibility pilot, concluded that *'respondents in the pilot study coped with most questions well and did not find them particularly difficult to answer'* and that *'a survey of cognitively able residents in care homes is feasible'*.

Alternative respondents

Purdon et al. (2008) draws upon previous research conducted by NatCen in residential and nursing care homes to estimate that in as many as in 60 per cent of cases residents will be too cognitively impaired or physically frail to participate in a survey interview. In these cases, it is proposed that researchers will attempt to gain responses from an alternative respondent able to answer on the residents behalf (subject to appropriate ethical approvals). It will therefore be important, when designing survey questions, to consider whether other residents, staff, family or friends will be able to answer the questions on behalf of residents.

In interviews conducted with residents and family members for this study, there was a widespread view expressed that residents generally did not know much about the treatment of other residents unless they were sharing a room with them. We were told that residents did not talk much to each other which observation seemed to suggest was the case. This may have been due to factors such as illness, cognitive impairments, the presence of televisions in communal areas, medication, lack of mobility, depression or other factors. Other residents were bed-ridden and confined to their rooms. Purdon et al. (2008, p 13.) found that in the feasibility pilot, *'residents sometimes struggled to talk about the experiences of other residents'* although Purdon et al. believed that many of these problems could be overcome with good questionnaire design.

Residents interviewed for this study, confirmed the findings of Purdon et al. (2008), and told us that family members, friends and visitors are often not likely to go into bedrooms or be there during care-giving. Even very frequent visitors, we were informed by residents, may only sit in the communal living

room with residents for a couple of hours. Family members we spoke to believed, however, that the resident would tell them of any mistreatment they experienced although it is not clear whether this is generally the case. Professor Catherine Hawes (personal interview carried out for this study) also suggested that family members can be unwilling to be critical of staff since they are unable to contemplate that they have left their relative in a place that is not treating them well. Professor Thomas Goergen (personal interview carried out for this study) interviewed family members for his research and found their knowledge of their relative's care was often not very detailed and that, although they could be critical of the home, that they were generally unspecific in their complaints. These findings suggest that family members are potentially both lacking knowledge about their relative's care and are unreliable informants, confirming the views of Purdon et al. (2008, p14) that family members should only be used if no cognitively able resident can report on the cognitively impaired resident's behalf.

As Purdon et al. (2008) note, training of interviewers to select the most appropriate alternative respondent and rigorous questionnaire development and testing will be highly important to address the challenges.

Key points and recommendations: Length, scope and answerability

- Estimates from residents and their families on manageable interview length ranged from 15 minutes to 35-40 minutes, with few residents thought to be able to sustain an interview at the upper limit. Interviews also often need to be paced to meet the needs of potentially frail residents and it can take a long time to cover a small number of questions
- Introductory questions are needed to screen for cognitive impairment and neutral questions should be used to 'close down' an interview. Possible areas of inquiry are numerous and some issues may require multiple questions. This suggests a need to heavily focus on issues of key interest and to accept that all areas of mistreatment cannot be feasibly covered in a resident interview.
- There exists no ultimate list of core measures that should be covered. However, researchers should take into account the reasonableness criterion of the perpetrator knowing, or being reasonably expected to know, that their action or inaction would cause harm. They should include a range of different types of mistreatment, various areas of care and activity and strike a balance between more serious and lower level incidents. They should focus on those areas that residents are most able to provide accurate and robust information about and on behaviours that most people agree constitute relatively unambiguous examples of mistreatment.
- The questionnaire should be piloted and checked against the concerns of residents; for example, having staff knock on a door before entering was

- Time periods/ frequency recall is likely to be challenging for those living in care homes and there are few markers which might help residents 'anchor' their experience to a specific time. Residents may also not have the relevant knowledge to answer some questions such as questions about over-medication.
- Gaining estimates using alternative respondents will be challenging. It was thought that residents' knowledge about the treatment of other residents may often be limited. Family and friends may not go into bedrooms or be present during care-giving and evidence suggests that their knowledge of their relative's care is not always very detailed. Training of interviewers to select the most appropriate alternative respondent and rigorous questionnaire development and testing will be highly important.

Chapter 7: Organisation

Service failure and poor quality care

Following earlier studies, the approach used in the community survey was to view mistreatment as consisting of one-on-one incidents, involving identifiable perpetrators. In fact, perpetrator groups were drawn explicitly so as to try to exclude incidents related to general service failure. In the case of paid care-workers in particular, however, the distinction between mistreatment and service failure was not always easy to make. For example, one survey respondent cited neglect by a paid care worker (O'Keeffe et al., 2007). However, in a follow-up qualitative interview it seemed that the problem lay less with any individual care worker but rather with an agency that sometimes failed to allocate a worker (Mowlam et al., 2007).

A survey of abuse, neglect and loss of dignity in residential and nursing care settings will inevitably involve negotiating considerably more incidents of poor care and service failure since residents live in an institution and rely on the provision of care services in almost all aspects of their lives, from their immediate living environment to the provision of specific forms of daily care. In practice, this means that there are likely to be numerous reports involving a series of incidents with multiple perpetrators as well as, potentially, incidents involving an apparent single perpetrator but where organisational constraints have played a significant role in determining the perpetrator's actions. For example, Hawes (2003), in her work with care facility staff in the USA, found strong evidence that staff retaliating when confronted with aggressive behaviour from residents occurred because of failures in the provision of adequate staff training, with staff clearly believing that these behaviours were intentional rather than understanding them to be symptomatic of cognitive impairment.

It would be feasible to attempt to exclude service failures and general poor levels of care from a survey in care settings. Professor Catherine Hawes, for example, is developing an approach for a prospective survey of residents living in care facilities in the US that focuses on measuring intentional abuse and wilful neglect and excluding more general problems of poor levels of care. However, we believe it is the intention of a prospective UK survey of residents living in care settings to measure a range of harms and mistreatment, including those which occur due to service failure and organisational factors. The inclusion of loss of dignity, in particular, requires that the survey cover poor care levels as well as incidents that involve specific individual perpetrators committing abusive or neglectful acts. We believe this to be a useful and appropriate approach given the significant impact of poor care levels on residents' well-being and evidence suggesting that poor care is a potentially significant problem. It may also be a helpful approach given that abuse can also sometimes be hard to distinguish from poor care levels; in fact, these may reflect different ends of a spectrum rather than be distinct phenomena with abusive behaviours potentially becoming institutionalised to

varying degrees. Consequently, we propose that a survey in residential and nursing care settings should actively include organisational and service failure and poor levels or quality of care, as well as intentional or active abuse and wilful neglect.

The responsibilities of providers

The care home is both a home where residents live and a workplace. As with any workplace, the organisational context sets a range of constraints and parameters which influence how individual staff carry out their work. These cover, for example, staff levels, policies, training, equipment, physical building and location, supervision, leadership and cultures of acceptable practice. These factors shape the nature and levels of care provided and may also be implicated in more specific acts of mistreatment (e.g. lack of clear procedures and training and/or poor levels of supervision)

The organisation itself (in the form of the 'registered person') is in a position of trust towards residents with there being clear organisational responsibilities to ensure quality of care, over and above the specific responsibilities and duties that fall upon staff members individually. Some of these obligations are set out in *Care Homes for Older People: National Minimum Standards. Care Homes Regulations [third edition]* (2003, Part III: Conduct of Care Home):

- is to 'ensure that the care home is conducted so as to promote and make proper provision for the health and welfare of service users' – regulation 12[1]
- shall 'so far as practicable enable service users to make decisions with respect to the care they are to receive and their health and welfare' – regulation 12[2]
- shall 'so far as practicable ascertain and take into account their [service users'] wishes and feelings' – regulation 12[3]
- conduct the home 'in a manner which respects the privacy and dignity of service users' – regulation 12[4a]
- is to ensure that 'unnecessary risks to the health or safety of service users are identified and so far as possible eliminated' – regulation 13[4c]
- is to 'make suitable arrangements to provide a safe system for moving and handling service users' – regulation 13[5]
- is to 'makes the service user's plan available to the service user and keep the service user's plan under review' – regulation 15[2]

Organisational features and examining their relationship to mistreatment

We propose, therefore, that the survey actively gather data relating to organisational context. In particular, consultees at a stakeholder event held for this study identified the following factors as being indicative of, or associated with, organisational failure and poor quality care:

- low staff: resident ratios
- staff burnout and stress
- institutional resistance to change and improvement
- lack of regular or appropriate training
- lack of regular or appropriate supervision
- negative ethos or culture about acceptable practice
- high levels of staff sickness
- high staff turnover
- absence of recorded policies and procedures
- policies and procedures not widely known about and/ or implemented;

This reflects many of the factors reflected in relevant literature. In addition, however, Pillemer and Moore (1989) identified:

- staff attitudes of thinking that the residents are like children
- staff having a personal life that is stressful
- high levels of conflict between staff and between staff and residents
- staff frequently thinking of quitting their jobs.

There is also evidence to suggest that staff do not always feel able to report incidents of mistreatment or poor care. Hawes (2003), for example, found a considerable mismatch between the number of staff who said they had witnessed mistreatment compared to the number who said they had reported it. This suggests that it would be useful to enquire about whether staff feel they can report incidents that they observe and how they believe these will be handled.

Some forms of mistreatment may also benefit from being placed in an organisational context. For example, high levels of restraint are likely to be related to poor organisational policies and practices on restraint (CSCI, 2007). It may be helpful therefore to explore correlations between high (and low) levels of restraint and different types of restraint with measures specifically related to restraint such as restraint policies, behaviour management support and training in alternative methods for dealing with aggressive behaviour such as de-escalation techniques and therapeutic approaches (CSCI, 2007).

Asking questions about the organisational context will enable a better understanding of the link between organisational features and the nature and incidence of mistreatment, poor care and loss of dignity. The intention would not be to identify 'bad homes'. All correlations would be conducted at an aggregate level with the survey sample including small numbers of staff/ residents/ family members across a large number of homes such that it would not be possible to draw meaningful conclusions about individual homes.

The issue of multiple perpetrators

Mistreatment that reflects poor standards of care and/or institutionalised abuse, neglect or loss of dignity is likely to show itself in the form of incidents with multiple perpetrators. This has implications for the way in which perpetrators are recorded. In the community survey, where questions about incidents involved thresholds, the presumption was that the repeated incidents were perpetrated by the same individual. This makes sense where an older person is receiving care from one, two or possibly three carers. However, in residential or nursing care, residents will be looked after by a wide range of carers and an alternative approach might be required.

Professor Thomas Goergen (personal interview conducted for this study), in his research, asked residents for the class of perpetrator (e.g. spouse or staff member). However, he pointed out that if a respondent had identified six occurrences of mistreatment perpetrated by staff, he had no way of knowing if this was six separate staff members committing mistreatment or the same staff member repeating the behaviour six times. This could represent poor practice across staff in the institution or one problem staff member. The implications for interpreting the data and for policy response are very different and ideally we would want to distinguish between these different scenarios. The simplest approach would be to ask for the class of perpetrator and, in the case of multiple incidents, also ask if the perpetrators were the same person or different people, although this will add to the burden on interview length.

Professor Thomas Goergen experienced a similar problem with neglectful acts in that he asked respondents for the class of perpetrator who they thought should have provided the care or assistance needed but, in the case of multiple incidents, he was unable to distinguish poor care standards from repeated acts of neglect perpetrated by specific staff members. One could, in these instances, ask a respondent whether the neglect was general or whether there was a specific individual who repeatedly did not perform the tasks needed. Such a question would need careful development and testing to ensure it is capable of eliciting the appropriate distinction. It will also add additional burden to the interview length.

The role of staff in a survey

Staff can provide data on different levels . They can report on organisational factors; on own attitudes and potentially on individual incidents of mistreatment/ loss of dignity. Purdon et al. (2008) also pointed to existing sources of staff data that could be used (an area that is being further explored in a study on secondary sources of data, conducted by a team led by Jill Manthorpe at king's College London as part of the same research programme) but these will not be linkable to data collected in the current survey. Other sources of information on the organisation could come from the home manager and from documentary sources.

Key points and recommendations: Organisation

- The approach in the community survey was to view mistreatment as consisting of one-on-one incidents, involving identifiable perpetrators with perpetrator groups drawn so as to exclude incidents related to general service failure. However, an exploration of abuse, neglect and loss of dignity in an institutional setting will inevitably involve addressing issues of service failure and poor quality care
- The organisation itself (in the form of the 'registered person') is in a position of trust towards residents with there being clear organisational responsibilities to ensure quality of care. This is over and above the obligations on individual staff members to provide good quality care. The organisation also sets a range of constraints and parameters which influence how individual staff carry out their work
- We propose that the survey gather data relating to organisational features so as to explore links with the nature and incidence of mistreatment. The intention would not be to identify 'bad homes'. Analysis would be conducted at an aggregate level with the survey sample including small numbers of respondents across a large number of homes such that it would not be possible to draw meaningful conclusions about individual homes
- In residential or nursing care, multiple incidents of mistreatment may represent repeated mistreatment by the same person or mistreatment by a range of different staff members. Each of these scenarios has different implications for policy and practice and it is important to be able to distinguish between these

Appendix 1: The mapping of existing definitions

(c) Indicates a definition used in the community survey (O' Keeffe et al., 2007)

FINANCIAL		
Theft/ fraud		
Stolen (or attempted to steal) money, possessions or property (C)		<ul style="list-style-type: none"> - Hudson (1991) - Saveman et al (1999) - Department of Health (2000) - Furness (2006) - Brandl et al (2007) - Hussein et al (2007) - Crosby et al (2008) - Magee et al (2008) - World Health Organisation (2008) - Cass et al (2009) - NCEA website
Control over access to personal possessions		<ul style="list-style-type: none"> - Help the Aged (2008)
Made you (or tried to make you) give money, possessions or property (C)	Including getting residents to sign documents against their will, use of threats and intimidation etc.	<ul style="list-style-type: none"> - Crosby et al (2008) - World Health Organisation (2008) - Wright et al (2009) - NCEA website
Used (or tried to use) fraud to take money, possessions or property (C)	e.g. forging signature, cashing cheques without authorisation, deceiving person into signing a document, improper use of power of attorney, fraudulent actions pertaining to wills, property etc.	<ul style="list-style-type: none"> - Halamandaris (1983) - Harris (1999) - Department of Health (2000) - Harris and Benson (2000)

		<ul style="list-style-type: none"> - Crosby et al (2008) - World Health Organisation (2008) - NCEA website
Taken or kept (or tried to take or keep) power of attorney (C)	Needs to be fraudulent intent to be abusive	<ul style="list-style-type: none"> - Crosby et al (2008) - Peri et al (2008) - NCEA website
Other financial exploitation		
Family acting to ensure that resident is given lower standard of care than needed or wanted in order to maintain assets for purposes of maximising inheritance	Very difficult to ask a simple question about. Involves assessing level of care received, whether it's less than needed or wanted, whether family are preventing or in some way discouraging a higher level of care and their intentions in doing so.	<ul style="list-style-type: none"> - Hudson (1991) - Crosby et al (2008) - NCEA website
Not being either rehabilitated or moved to higher support care because of financial incentives for institution in keeping older person in existing care setting	This is similar to the item above, but relates to the actions of the care institution rather than family members; encounters the same difficulties as the item above.	<ul style="list-style-type: none"> - Clough (1999) - World Health Organisation (2008)
Charging for services (e.g. bathing) and/or over-charging	May be financial exploitation or may be intended to limit demand	<ul style="list-style-type: none"> - Clough (1999)
Failure to protect financial autonomy		
Not having (sufficient) money of own for spending including being denied opportunity/ right to access personal funds	Will depend on policies of the home, levels of cognitive impairment and family involvement	<ul style="list-style-type: none"> - Saveman et al (1999) - World Health Organization/ INPEA (2002) - Zink & Fisher (2006) - Peri et al (2008) - Wright et al (2009)

Not being given appropriate assistance to manage/ monitor financial affairs	e.g. help reading bank statements	- Peri et al (2008) - Cass et al (2009) - Dignity in Care blog
Not being given appropriate assistance to access benefits		- Crosby et al (2008)
PSYCHOLOGICAL		
Verbal abuse/ humiliation		
Insulted you, called you names, sworn at you or made unjustified accusations (C)		- Pillemer & Moore (1989) - Department of Health (2000) - Daly & Jogerst (2006) - McDonald et al (2008) - World Health Organisation (2008) - Wright et al (2009) - NCEA website
Threatened you (C)	e.g. to hurt you, to abandon you, with punishment etc.	- Pillemer & Moore (1989) - Department of Health (2000) - Zink & Fisher (2006) - McDonald et al (2008) - World Health Organisation (2008) - Wright et al (2009) - NCEA website
Shouted at you (C)		- World Health Organisation (2008)
Undermined or belittled you (C)		- Mains (1994) - Stones (1995) - Clough (1999) - Horton (2004) - Furness (2006)

		<ul style="list-style-type: none"> - Hussein et al (2007) - McDonald et al (2008) - World Health Organisation (2008) - NCEA website
Staff make racist, ageist, sexist comments or jokes		<ul style="list-style-type: none"> - Department of Health (2003a) - World Health Organization/ INPEA (2002) - Health Information and Quality Authority (2008)
Staff laugh at residents, play tricks on them and/or treat serious incidents as a joke, use sarcasm		<ul style="list-style-type: none"> - Clough (1999) - Furness (2006)
Impatience, being rushed and lack of courtesy		<ul style="list-style-type: none"> - Department of Health (2003a) - Griffin-Heslin (2005) - Barnes et al (2006) - Department of Health (2006c) - Dignity in Care site (2009)
Patronising and/or infantilising way of addressing	e.g. telling off, talking down to, speaking to in a bossy or scolding way	<ul style="list-style-type: none"> - Saveman et al (1999) - Department of Health (2006c) - Help the Aged (2006)
Not using requested/ desired term of address/ using overly informal or familiar terms of address		<ul style="list-style-type: none"> - Commission for Social Care Inspection (2003) - Department of Health (2003a) - Department of Health (2006c) - Commission for Healthcare Audit and Inspection

		<p>(2007)</p> <ul style="list-style-type: none"> - Magee et al (2008) - Cass et al (2009) - Dignity in Care site (2009)
Isolation/ exclusion/ lack of inter-personal interaction		
Excluded you or repeatedly ignored you (e.g. 'silent treatment') (C)		<ul style="list-style-type: none"> - Chan (2004) - Barnes et al (2006) - DoH (2006a) - NCEA website
Lack of socialising/ inter-personal engagement	e.g. Staff make time to talk with residents., voluntary befriending services, helped to access other social networks.	<ul style="list-style-type: none"> - Cass et al (2009) - Wright et al (2009) - Health Information and Quality Authority (2008) - Social Care Institute for Excellence (2008)
Lack of appropriate communication methods with those with people with sensory impairments or dementia	e.g. visual aids, non-verbal communication	<ul style="list-style-type: none"> - Magee et al (2008) - Cass et al (2009)
Availability of interpreters or staff who speak language of resident		<ul style="list-style-type: none"> - CHAI (2007) - Help the Aged (2008)
Lack of engagement with wider community/ Lack of assistance to travel outside care-home	What constitutes engagement with wider community? Capacity to engage with wider community may vary according to state of health.	<ul style="list-style-type: none"> - Department of Health (2000) - Barnes et al (2006) - Magee et al (2008) - World Health Organization (2008) - Cass et al (2009) - NCEA website

		- Dignity in Care blog
Lack of enhanced support at times of acute distress in a manner that takes account of resident's preferences		- Hudson (1991) - Department of Health (2005) - Health Information and Quality Authority (2008)
Not talking, interacting while delivering care		- Horton (2004) - Department of Health (2006a) - (Magee et al (2008) - Dignity in Care site (2009)
Staff forget when family and friends are due to visit and do not ensure appropriate arrangements		- Magee et al (2008)
Lack of reminiscence activity for dementia sufferers		- Cass et al (2009)
Lack of purposeful activity		
No or few activities for residents; lack of stimulation		- Clough (1999) - Department of Health (2006d) - Help the Aged (2006) - Magee et al (2008)
Not feeling needed, having sense of purpose/ role		- Mains (1994) - Chan (2004) - Help the Aged (2006) - Griffin-Heslin (2005) - Dignity in care site
Not identifying/ using person's skills, abilities		- Cass et al (2009) - Help the Aged (2006)

Residents not permitted to participate in/ contribute to day to day running of the home	Not clear in what way this would be possible	- Cass et al (2009)
Lack of respect for personal choice and values		
Staff should seek and respect individual choices about own care, supporting residents to make decisions where needed, including those with cognitive or communication difficulties	Randers and Mattiason set out good practice of supporting those with cognitive difficulties including documenting person's previous habits and preferences & using those to guide or gaining information on preferences from others who know resident well	- World Health Organization/ INPEA (2002) - Chan (2004) - Bayer et al (2005) - Griffin-Heslin (2005) - Barnes et al (2006) - Department of Health (2006a) - Help the Aged (2006) - Commission for Social Care Inspection (2007) - Hussein et al (2007) - Magee et al (2008) - Cass et al (2009) - Randers and Mattiason, (2004)
No choice in décor of own room		- (Magee et al (2008) - Cass et al (2009)
Lack of choice concerning appearance	e.g. dress, hair etc.	- Magee et al (2008) - Cass et al (2009)
Not wearing own clothing		- Health Information and Quality Authority (2008) - Cass et al (2009)
Lack of choice concerning schedule		- Help the Aged (2006)

Lack of maintenance of respectable appearance		<ul style="list-style-type: none"> - Barnes et al (2006) - Department of Health (2006d) - Cass et al (2009)
Sensitivity and responsiveness to culture, religion, age, disability, gender and sexuality	Needs further specification e.g. in relation to food, customs, terminology, attitudes and behaviour etc. Subsumes considerable number of possible behaviours.	<ul style="list-style-type: none"> - Department of Health (2003a) - Department of Health (2006d) - Magee et al (2008)
Controlling & bullying		
Threatened to harm others that you care about (C)		<ul style="list-style-type: none"> - Wolf et al (2002) - O'Keeffe et al (2007)
Prevented you from seeing others that you care about (C)		<ul style="list-style-type: none"> - Zink & Fisher (2006) - Magee et al (2008) - World Health Organization (2008) - NCEA website
Checking up on resident (in a way that makes them feel afraid)	<p>An example of an action than is defined both by behaviour and impact/ perception.</p> <p>However some behaviour may make someone feel angry but not afraid, or they may just accept it as the way things are done even though the checking up is excessive.</p>	<ul style="list-style-type: none"> - Zink & Fisher (2006)
Miscellaneous bullying by other residents	e.g. residents demanding that a chair is 'theirs', hogging the TV remote control	<ul style="list-style-type: none"> - Wolf et al (2002) - Peri et al (2008)
Hostile attitude to residents' visitors		<ul style="list-style-type: none"> - Department of Health (2003a) - Magee et al (2008)

Denied food or privileges as punishment		- Pillemer & Moore (1989)
Lack of information and explanation		
Failure to provide adequate explanation and information, in appropriate format, free of jargon	In relation to what ... needs specifying. Ideally older people will be involved in developing information resources.	- Barnes et al (2006) - Commission for Healthcare Audit and Inspection (2007) - Magee et al (2008) - World Health Organization (2008) - Cass et al (2009)
PHYSICAL		
Physical violence		
Slapped you (C)		- Department of Health (2000) - Zink & Fisher (2006) - McDonald (2007) - Wright et al (2009) - NCEA website
Grabbed, pushed or shoved you (C)		- Pillemer & Moore (1989) - Department of Health (2000) - Zink & Fisher (2006) - McDonald (2007) - World Health Organization (2008) - Wright et al (2009) - NCEA website
Kicked, bit or hit you with a fist (C)		- Pillemer & Moore (1989) - Department of Health (2000) - Daly & Jogerst (2006)

		<ul style="list-style-type: none"> - Zink & Fisher (2006) - World Health Organization (2008) - NCEA website
Burned or scalded you (C)		<ul style="list-style-type: none"> - Hawes (2002) - World Health Organization (2008) - Wright et al (2009) - NCEA website
Threatened you with (or used) a knife, gun or other weapon (C)		<ul style="list-style-type: none"> - O'Keeffe et al (2007)
Choked or attempted to drown you		<ul style="list-style-type: none"> - Zink & Fisher (2006)
Hit you with an object		<ul style="list-style-type: none"> - Pillemer & Moore (1989) - Zink & Fisher (2006) - McDonald (2007) - NCEA website
Other violence (C)	Examples in the literature include shaking, pulling hair, electric shock, exposure to noxious odours, scalding with hot water, opening windows or removing blankets at night, for example, or any (other) physical 'punishments'	<ul style="list-style-type: none"> - Clough (1999) - Hawes (2002) - Daly & Jogerst (2006) - NCEA website
Physical forms of restraint		
	<p>Clough makes the point that restraint is not necessarily illegitimate and while some definitions define restraint as abuse, on the whole definitions are qualified by the terms such as 'excessive', 'inappropriate' or 'beyond what you would think was needed' (Pillemer and Moore, 1989)</p> <p>Clough has a typology of restraint</p>	<ul style="list-style-type: none"> - Pillemer & Moore (1989) - Stones (1995) - Department of Health (2000) - Juklestad (2001) - Wolf et al (2002) - Commission for Social Care

	covering physical restraint; physical intervention (human restraint such as being blocked, forcibly moved etc); chemical restraint: environmental restraint and surveillance.	<p>Inspection (2007)</p> <ul style="list-style-type: none"> - Magee et al (2008) - Wright et al (2009) - Kalaga & Kingston (2007)
Tied you down (C)		<ul style="list-style-type: none"> - Juklestad (2001) - Daly & Jogerst, (2006) - Commission for Social Care Inspection (2007) - McDonald (2007) - Clough (1999) - World Health Organization (2008) - Clough (1999)
Locked you in your room (C)		<ul style="list-style-type: none"> - Daly & Jogerst, (2006) - CSCI (2007) - O'Keeffe et al (2007) - Clough (1999)
Given you drugs or too much medicine in order to control you/ to make you docile (C)		<ul style="list-style-type: none"> - Stones (1995) - Department of Health (2000) - Juklestad (2001) - Burstow, P. (2001, 2003, 2005, 2008) - Wolf et al (2002) - Daly & Jogerst (2006) - Commission for Social Care

		<p>Inspection (2007)</p> <ul style="list-style-type: none"> - Brandl et al (2007) - Kalaga & Kingston (2007) - McDonald (2007) - NCEA website - Clough (1999)
Unnecessary use of catheters, feeding tubes/ force feeding etc.	How to determine when they are unnecessary?	<ul style="list-style-type: none"> - Hawes (2002) - CSCI (2007) - Clough (1999)
Not allowed to move freely around home (N)	<p>e.g. Not allowed to go outside into garden.</p> <p>However, There may be areas where reasonably restricted from going such as kitchens, utility rooms etc.</p>	<ul style="list-style-type: none"> - Juklestad (2001) - Commission for Social Care Inspection (2007) - World Health Organization (2008) - Clough (1999)
Unnecessary use of bed rails	Are they ever necessary? Under what circumstances?	<ul style="list-style-type: none"> - Commission for Social Care Inspection (2007) - Kalaga & Kingston (2007) - Clough (1999)
Chairs that person is unable to get out of unassisted (where able to get in and out of other chairs)		<ul style="list-style-type: none"> - Commission for Social Care Inspection (2007) - Clough (1999)
Ignoring calls/ requests for assistance/ call button		<ul style="list-style-type: none"> - Hawes (2002) - Commission for Social Care Inspection (2007) - Clough (1999)
Held someone down, physically preventing them going where they want, forcibly moving someone.		<ul style="list-style-type: none"> - Department of Health (2000) - Wolf et al (2002) - Commission for Social Care

		<p>Inspection (2007)</p> <p>- World Health Organization (2008)</p> <p>- Clough (1999)</p>
Surveillance	e.g. CCTV	- Clough (1999)
Restrained you in any other way (C)	May need explanation as covers many different forms	<p>O'Keeffe et al (2007)</p> <p>- Clough (1999)</p>
Inappropriate handling		
Being man-handled, handled unnecessarily roughly		<p>- Saveman et al (1999)</p> <p>- Furness (2006)</p>
One rather than two person transfers (when moving people manually)		- Hawes (2002)
Hoists to be avoided where it aggravates pain		- Help the Aged (2008)
Not being given warranted physical assistance		- Hudson (1991)
Nutrition/ hydration		
Lack of appealing, good quality food; poor nutrition	Pureed foods, where required, should be kept separate from each other and it should be clear what they are.	<p>- Stones (1995)</p> <p>- Hussein et al (2007)</p> <p>- Magee et al (2008)</p> <p>- Cass et al (2009)</p>
Lack of availability of food/ snacks between meals		- Cass et al (2009)
Residents rushed to eat and drink/ interruptions to mealtimes		- Cass et al (2009)
Lack of appropriate and dignified assistance to eat food/ drink	Assistance should be given as discreetly as possible (e.g. serviettes not bibs; adapted cutlery or finger food rather than hand-feeding; helped to use knife and	<p>- Department of Health (2006a)</p> <p>- Cass et al (2009)</p>

	<p>fork rather than finger food if possible)</p> <p>Privacy should be offered to those who have difficulty eating for their dignity.</p>	- Dignity in Care site (2009)
Lack of freely available and accessible drinking water		- Magee et al (2008)
Failure to address significant weight loss	e.g. by measuring food and fluid intake	- Cass et al (2009)
With-holding food in punishment		- Department of Health (2000) - World Health Organization (2008)
Lack of consultation on menus with residents; not taking account of individual preferences		- Magee et al (2008) - Cass et al (2009)
Poor environment		
Lack of clean, tidy environment free from unpleasant odours		- Barnes et al (2006) - Magee et al (2008) - Cass et al (2009)
Environment not adapted to needs of residents	e.g. for those with mobility impairments	- Magee et al (2008) - World Health Organisation (2008)
Poor/ lack of medical care		
Being given insufficient information about medication		- Department of Health (2000)

Not being given needed medication/ medical attention	including hearing aids, glasses and prostheses and oral/ dental care	<ul style="list-style-type: none"> - Department of Health (2000) - Hawes (2002) - Barnes (2006) - Zink and Fisher (2006) - Brandl et al (2007) - McDonald (2007) - Magee et al (2008) - World Health Organisation (2008)
Attending medical appointments without staff ensuring relevant information/ paperwork or bringing residents at the wrong time.		- Magee et al (2008)
Lack of adequate pain control		<ul style="list-style-type: none"> - Department of Health (2006c) - Magee et al (2008)
Staff forget when professionals are due to visit and do not ensure appropriate arrangements		- Magee et al (2008)
Failure to gain professional advice for behaviour such as extreme distress, anxiety, aggression		- Health Information and Quality Authority (2008)
Failure to take action to prevent bed/ pressure sores		<ul style="list-style-type: none"> - Wolf et al (2002) - Kalaga & Kingston (2007) - Wright et al (2009)
Poor/ inappropriate/ undignified personal care		
Is not appropriately dressed; too hot or cold		- Magee et al (2008)
Insufficient exercise/ not doing 'range of motion' exercises		<ul style="list-style-type: none"> - Hawes (2002) - Kalaga & Kingston (2007)

Residents not supported to have good personal hygiene – bathing, shaving and hair removal, oral, nails & podiatry, laundry.	May include lack of assistance or failure to provide toiletries and other requisites.	- Stones (1995) - Hawes (2002) - Magee et al (2008) - Cass et al (2009)
'Forgetting residents' and leaving them e.g. in the toilet, on a commode		- Peri et al (2008)
Incontinence pads – either over-use to avoid taking to bathroom or letting people sit in soiled pads; Or letting people sit with soiled clothing		- Clough (1999) - Hawes (2002) - Magee et al (2008)
Being forced to use commode rather than be helped to bathroom		- Department of Health (2006c) - Dignity in care site
Taking life		
Taking life - Method not specified in literature but could feasibly include with-holding food, hydration and/or medication		- Clough (1999) - Kalaga & Kingston (2007) - Magee et al (2008)
PRIVACY		
General issues		- Department of Health (2003b) - Griffin-Heslin, (2005) - Barnes et al (2006) - Department of Health (2006d)

Lack of privacy in bathrooms and toilets/ commodes		<ul style="list-style-type: none"> - Stones (1995) - Clough (1999) - Commission for Social Care Inspection (2003) - Barnes et al (2006) - Kalaga & Kingston (2007) - Magee et al (2008) - Cass et al (2009)
Lack of privacy in bedrooms	e.g. - Staff and others not knocking/ requesting permission before entering.	<ul style="list-style-type: none"> - Stones (1995) - Clough (1999) - Commission for Social Care Inspection (2003) - Barnes et al (2006) - Kalaga & Kingston (2007) - Magee et al (2008) - Cass et al (2009)
Lack of privacy for medical consultation with, and examination by, health professionals		<ul style="list-style-type: none"> - Commission for Social Care Inspection (2003) - Zink & Fisher (2006) - Magee et al (2008) - Health Information and Quality Authority (2008)
Lack of privacy for consultations with legal and financial advisors	Presumably with appropriate protection of vulnerable	<ul style="list-style-type: none"> - Commission for Social Care Inspection (2003) - Health Information and Quality Authority (2008) - World Health Organisation (2008)

Lack of privacy for expressions of intimacy and sexuality (with appropriate assessment of risk to vulnerable people)		<ul style="list-style-type: none"> - Chan (2004) - Help the Aged (2006) - Health Information and Quality Authority (2008) - Cass et al (2009)
Lack of privacy in communications - when meeting with friends and relatives, mail being opened by others, not receiving mail promptly, no private use of telephone		<ul style="list-style-type: none"> - Commission for Social Care Inspection (2003) - World Health Organisation (2008) - Cass et al (2009)
Lack of ability to spend time alone when wanted		<ul style="list-style-type: none"> - Health Information and Quality Authority (2008)
Lack of privacy of care received prior to and at time of death		<ul style="list-style-type: none"> - Commission for Social Care Inspection (2003) - Health Information and Quality Authority (2008)
Lack of privacy of personal information – only those who need information to carry out work should have access to personal records/ information		<ul style="list-style-type: none"> - Department of Health (2003b) - Health Information and Quality Authority (2008) - Magee et al (2008)
Overcrowded conditions		<ul style="list-style-type: none"> - Clough (1999) - World Health Organisation (2008)
Inappropriate intimate care practices such as lining up three naked people to bathe them		<ul style="list-style-type: none"> - Clough (1999)
SEXUAL		

General issues		<ul style="list-style-type: none"> - Ramsey-Klawnsnik (1993 & 1996) - Clarke and Pierson (1999) - Dergal & de Nobrega (2000) - Burgess et al (2002) - Wolf et al (2002) - Hussein et al (2007) - McDonald (2007) - World Health Organisation (2008) - NCEA website - Clough (1999)
Non-contact sexual abuse		
Talked to you in a sexual way that made you feel uncomfortable (serious teasing, innuendo, harassment) (C)		- Wright et al (2009)
Made you (or tried to make you) watch pornography against your will (or in situation where resident could not give consent) (C)		- Wright et al (2009)
Coerced nudity, voyeurism 'peeping tom'	Care may need to be taken to avoid residents thinking we are referring to incidents during legitimate medical examination	<ul style="list-style-type: none"> - Wright et al (2009) - NCEA website
Non-consensual sexually explicit photographing		<ul style="list-style-type: none"> - Wright et al (2009) - NCEA website
Indecent exposure		- Wright et al (2009)
Contact sexual abuse		
Touched you (or tried to touch you) in a sexual way against your will (or in situation where resident could not give consent) (C)		<ul style="list-style-type: none"> - Clough (1999) - Zink & Fisher (2006) - McDonald (2007) - World Health Organisation (2008) - Wright et al (2009) - NCEA website
Had (or tried to have) sexual		- Department of Health (2000)

intercourse with you against your will (or in situation where resident could not give consent) (c)		<ul style="list-style-type: none"> - Horton (2004) - Zink & Fisher (2006) - McDonald (2007) - NCEA website
Penetrated vagina anus, mouth (or attempted to penetrate) with penis, fingers or objects against will (or in situation where resident could not give consent)	Care may need to be taken to avoid residents thinking we are referring to incidents during legitimate medical examination	<ul style="list-style-type: none"> - Wright et al (2009) - NCEA website
Attacked sexual parts		<ul style="list-style-type: none"> - Zink & Fisher (2006)
Inappropriately intimate touching of residents during administration of care.		<ul style="list-style-type: none"> - Dignity in Care site
ENGAGEMENT AND REDRESS		
Systems for user engagement		
Lack of systems for allowing residents to have a say in how services are provided, or residents not being aware of systems or knowing how to access them. Resident views not taken into account.		<ul style="list-style-type: none"> - Department of Health (2003a) - Chan (2004) - Barnes et al (2006) - Help the Aged (2006) - Magee et al (2008) - Cass et al (2009)
Not consulted on own care		<ul style="list-style-type: none"> - Bayer et al (2005) - Griffin-Heslin (2005) - Department of Health (2006a) - Help the Aged (2006)
Systems for redress		
Lack of systems available for complaining about services, or residents not being aware of systems, not knowing how or being supported to access them. Complaints not appropriately and promptly handled; complainant not being informed about progress and outcome. Complaints not used to inform service development and		<ul style="list-style-type: none"> - Department of Health (2006d) - Help the Aged (2006) - Magee et al (2008) - Cass et al (2009)

improvement; lack of clear information about what resident can do if not satisfied with outcome of complaint		
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Appendix 2: Behavioural Definitions in the UK Survey of Abuse and Neglect of Older People Living in the Community (O' Keeffe et al., 2007)

<p>Neglect</p>	<p>10 or more instances of neglect in the last 12 months OR less than 10 instances in the last 12 months but judged by the respondent to be “very serious” Respondent must have stated that they need and receive help with an activity, and that they have difficulty carrying out the activity by themselves. Neglect grouped into three categories:</p> <ul style="list-style-type: none"> - <i>Day to day activities (Shopping for groceries or clothes, Preparing meals, Doing routine housework, Travel or transport)</i> - <i>Personal care (Getting in and out of bed, Washing or bathing, Dressing or undressing, Eating, including cutting up food, Getting to and using toilet)</i> - <i>Help with correct dose and timing of medication</i>
<p>Financial abuse</p>	<p>1 or more instance of financial abuse in the last 12 months</p> <ul style="list-style-type: none"> - <i>Stolen money, possessions or property</i> - <i>Attempted to steal money, possessions or property</i> - <i>Made you give money, possessions or property</i> - <i>Tried to make you give money, possessions or property</i> - <i>Used fraud to take money, possessions or property</i> - <i>Tried to use fraud to take money, possessions or property</i> - <i>Taken or kept power of attorney</i> - <i>Tried to take or keep power of attorney</i>
<p>Psychological abuse</p>	<p>10 or more instances of psychological abuse in the last 12 months by the same person</p> <ul style="list-style-type: none"> - <i>Insulted you, called you names or sworn at you</i> - <i>Threatened you</i> - <i>Undermined or belittled what you do</i> - <i>Excluded you or repeatedly ignored you</i> - <i>Threatened to harm others that you care about</i> - <i>Prevented you from seeing others that you care about</i>
<p>Physical abuse</p>	<p>1 or more instance of physical abuse in the last 12 months</p> <ul style="list-style-type: none"> - <i>Slapped you</i> - <i>Grabbed, pushed or shoved you</i> - <i>Kicked, bit or hit you with a fist</i> - <i>Burned or scalded you</i> - <i>Threatened you with a knife, gun or other weapon</i> - <i>Used a knife, gun or other weapon</i> - <i>Done anything violent to you which you have not mentioned</i> - <i>Tied you down</i>

	<ul style="list-style-type: none"> - <i>Locked you in your room</i> - <i>Given you drugs or too much medicine in order to control you/ to make you docile</i> - <i>Restrained you in any other way</i>
<p>Sexual harassment / abuse</p>	<p>1 or more instance of sexual harassment or abuse in the last 12 months</p> <ul style="list-style-type: none"> - <i>Talked to you in a sexual way that made you feel uncomfortable</i> - <i>Touched you in a sexual way against your will</i> - <i>Tried to touch you in a sexual way against your will</i> - <i>Made you watch pornography against your will</i> - <i>Tried to make you watch pornography against your will</i> - <i>Had sexual intercourse with you against your will</i> - <i>Tried to have sexual intercourse with you against your will</i>

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