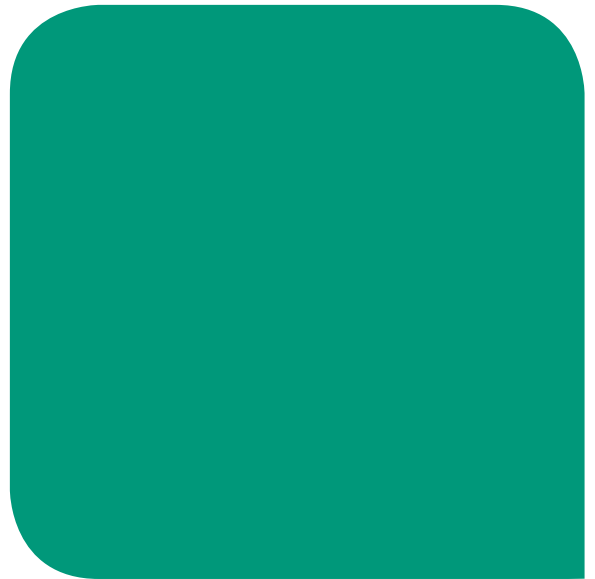**scie**

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Self-neglect and adult safeguarding: findings from research

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Executive summary

Introduction

The research reported here was commissioned by the Department of Health (DH). Conducted between December 2009 and May 2010, it comprised a scoping study of the concept of self-neglect as defined in the literature and interpreted in adult safeguarding practice. The report draws on a systematic review of the literature, workshops with senior managers and practitioners in specialist safeguarding roles, a focus group with adult social care practitioners and interviews with key informants.

The relationship between self-neglect and safeguarding in the UK is contested, in part because the current definition of abuse specifies harmful actions by someone other than the individual at risk. Safeguarding Adults Boards' policies and procedures commonly contain no reference to self-neglect; occasionally they explicitly exclude it or set criteria for its inclusion, for example, drawing a distinction between *unwillingness* to maintain health and safety and *inability* to do so. Safeguarding structures and communication channels are sometimes used to facilitate information sharing about situations of self-neglect, and to resolve questions of whether intervention can be made. In the US, conversely, self-neglect falls within the remit of adult protection services and is subject to mandatory reporting.

The concept of self-neglect

Manifestations of self-neglect as described in the literature are complex, as are the explanations offered. At one end of the spectrum, self-neglect is seen as a psycho-medical condition, in some cases a psychiatric syndrome, which may be associated with other accompanying mental disorders. Others take issue with a disease model of self-neglect, preferring to adopt a socio-cultural model which at its extreme sees self-neglect as a social construct influenced by social, cultural and professional values, in effect a value judgement as opposed to an objective phenomenon. In between lie social psychological models that consider the interplay of factors external and internal to the individual. Research has sought to isolate factors, biological, behavioural and social, that may be associated with, if not causative of, self-neglect, but without being able to integrate the correlations within an overarching explanatory model. Models of self-neglect thus encompass a complex interplay between mental, physical, social and environmental factors. Executive dysfunction – the inability to perform activities of daily living, even though the need for them may be understood – is seen as significant, and when this is accompanied by an inability to recognise unsafe living conditions, self-neglect may be the result.

The perceptions of people who neglect themselves have been less extensively researched, but where they have, emerging themes are pride in self-sufficiency, connectedness to place and possessions and behaviour that attempts to preserve continuity of identity and control. Traumatic histories and life-changing effects are also present in individuals' own accounts of their situation.

Self-neglect is reported mainly as occurring in older people, although it is also associated with mental ill health. Differentiation between inability and unwillingness

to care for oneself, and capacity to understand the consequences of one's actions, are crucial determinants of response. Professional tolerance of self-neglect as lifestyle choice is higher than when it accompanies physical/mental impairment. Professionals express uncertainty about causation and intervention.

Interventions

Capacity is a highly significant factor in both understanding and intervening in situations of self-neglect. Decision-making autonomy by those who have capacity is widely recognised and respected. There is strong professional commitment to autonomy in decision making and to the importance of supporting the individual's right to choose their own way of life, although other value positions, such as the promotion of dignity, or a duty of care, are sometimes also advanced as a rationale for interventions that are not explicitly sought by the individual.

The literature reveals that capacity is a complex attribute, involving not only the ability to understand the consequences of a decision but also the ability to execute the decision. Where *decisional capacity* is not accompanied by *executive capacity*, and thus overall capacity for autonomous action is impaired, 'best interests' intervention by professionals to safeguard wellbeing may be legitimate. Yet executive capacity does not routinely figure in capacity assessments, and there is a risk that its absence may not be recognised. There is concern too that capacity assessments may overlook the function-specific nature of capacity, with the result that apparent capacity to make simple decisions is assumed in relation to more complex ones.

In terms of evidence of effective interventions in self-neglect, there is little evidence in the literature of model programmes. Knowledge of legal frameworks for intervention, either where the individual lacks capacity or where, notwithstanding capacity, grounds for lawful removal are met, is seen as vital. But the legal rules are experienced as complex and may not be well understood. There was some consensus that decisions on whether and how to intervene in any given situation could and should be made through a robust system of interagency communication and risk sharing. Information sharing without the individual's consent, however, where that person has capacity, drew particularly heated debate, with significant legal and ethical concerns raised.

Sensitive and comprehensive assessment is emphasised, assisted where appropriate by effective screening tools that assist clinicians in identifying capabilities and risks; equally relationships and professional judgement remain valued as effective means of conducting assessments. Early intervention, before self-neglectful behaviour becomes entrenched, is seen as important. Cleaning interventions alone do not emerge as effective in the longer term, but assistance with daily living may be more so, particularly where self-neglect is linked to poor physical functioning. The literature endorses the value of interventions to support the routine daily living tasks; there is less evidence of the effectiveness of psychological interventions. Building good relationships is seen as key to maintaining the kind of contact that can enable interventions to be accepted with time, and decision-making capacity to be monitored.

Conclusions

The literature identifies the wide range of perspectives that inform professionals' understanding of self-neglect. There is, however, no conclusive evidence on causation, or on the effectiveness of particular interventions. There are tensions between respect for autonomy and a perceived duty to preserve health and wellbeing. The former principle may extend as far as recognising that an individual who chooses to die through self-neglect should not be prevented from doing so; the latter may engage the view that action should be taken, even if resisted, to preserve an individual's safety and dignity. Human rights arguments are engaged in support of either perspective.

The autonomy of an adult with capacity is likely to be respected, and efforts directed to building and maintaining supportive relationships through which services can in time be negotiated. Capacity assessments, however, may not take full account of the complex nature of capacity; the distinction in the literature between decisional and executive capacity is not found in practice, and its importance for determining responses to self-neglect may need to be considered further. While in the US situations involving self-neglect fall within the remit of adult protection services, in the UK they currently fall outside the definitions that regulate adult safeguarding activities. Responses are therefore diverse, and may be led through adult social care or through safeguarding procedures, depending on local arrangements. Whichever structure is used, strong emphasis is placed by practitioners on the importance of interagency communication, collaboration and the sharing of risk.

Part I: Introduction and methodology

1   Background

The research reported here was commissioned by the Department of Health (DH). It took place between December 2009 and May 2010 and had as its aim to undertake a scoping study of the concept of self-neglect as defined in the literature and interpreted in adult safeguarding practice.

Safeguarding adults is a multi-agency responsibility, guidance on which (*No secrets*, DH, 2000) has been subject to public and political scrutiny (DH, 2008, 2009, 2010). The core focus of *No secrets* is on interagency arrangements for protecting 'vulnerable adults' from abuse, with abuse defined as 'a violation of an adult's human and civil rights by any other person or persons'. Proposals to revise definitions relating to safeguarding adults are currently under consideration (Law Commission, 2010, 2011). Under the current definition of abuse, however, because in cases of self-neglect there is no 'other person' engaging in the violation of rights, the position of those individuals who may, with or without capacity, neglect their own safety is a contentious and debated aspect of adult safeguarding practice. Equally, the concept of self-neglect is in itself complex and contested, and requires careful exploration within the context of the principles of empowerment that underpin adult safeguarding, and the goals of choice and control in adult social care.

The overall aims of the research project were to scope the concept of self-neglect within the context of adult safeguarding in order to explore the following questions:

- How is self-neglect conceptualised?
- How do mental capacity and human rights have an impact on the conceptual framework?
- What is the interface between self-neglect and safeguarding?
- What is the nature of professional interventions?

2 Methodology

2.1 Overview of data sources

The study was designed to explore the concept of self-neglect primarily from a review of the literature. However, because it was conducted parallel to a companion study on the governance of adult safeguarding (Braye et al, 2011), a number of fieldwork opportunities arose and allowed exploration of self-neglect from the perspectives of adult safeguarding practitioners, managers and policy makers, and Safeguarding Adults Board members and chairs. Similarly, a range of Safeguarding Adults Boards' documentation was scrutinised for reference to self-neglect. The sources of data on which the findings reported here are based are listed below.

2.1.1 Systematic review of the literature

Extensive database searches identified 3,162 references potentially relevant to the research. The abstracts were screened for relevance and those deemed relevant were obtained in full text; ultimately 160 papers were included in the self-neglect literature review, and themes relevant to the research focus were extracted. Further details of the approach taken to the literature review are given in Appendix 1 (Overview of the literature review), Appendix 2 (Search terms and databases), Appendix 3 (Search results) and Appendix 4 (Keywording strategy).

2.1.2 Safeguarding specialists workshops

Three parallel workshops were held (two in London, one in Manchester), attended by Board chairs, directors of adult services, safeguarding leads and others with specialist safeguarding roles, including participants from the NHS and the police, to explore conceptual, policy and practice issues relating to self-neglect. Invitations were sent to all authorities through regional networks; the total number of participants was 44.

2.1.3 Practitioner workshop

With the support of a regional adult safeguarding network, a group attended by seven participants met to consider practice issues arising from cases of self-neglect, and the interface with safeguarding procedures in cases of this nature.

2.1.4 Key informant interviews

A small number (five) of key informants were interviewed, selected for their engagement with adult safeguarding in roles that gave them an overview perspective. Their views on and experiences of the interface between self-neglect and safeguarding were sought through a series of open-ended, topic-driven questions.

2.2 Ethical approval

The research team applied for and secured ethical approval for the project from the National Social Care Research Ethics Committee (REC reference number 09/IEC08/19).

Part II: Research findings

1   Introduction

This section reports on the scoping review of self-neglect in terms of both its conceptualisation and its interpretation in practice. It draws on the literature reviewed, on workshops which brought together directors of adult social services, Safeguarding Adult Board chairs and others with specialist safeguarding roles, on a focus group with practitioners in adult social care and on interviews with key informants. The findings are organised thematically, progressing through different approaches to defining self-neglect, considering questions of capacity in relation to self-neglect and then examining the evidence on how cases can most effectively be assessed and how to intervene.

The majority of the 160 references included in the literature review came from North America, a total of 119, of which the vast majority were from the US. Twenty references were from the British literature, of which 14 emerged from an English legislative and research context, and six from Scotland. Of the remainder, 10 were from other European countries (including France, Spain, Germany, Switzerland and Ireland), 5 from Australia, 1 from Brazil, and 5 from cross-continental collaborations. Further details of ways in which the literature may be categorised are included in Appendix 1.

While at first sight the geographical distribution might appear to be of only minor interest, it quickly became apparent during the course of the review that the different national contexts had a significant influence on the conceptualisation and development of the research conducted. This was particularly the case for the North American literature, as the unique configuration of responsibilities in cases of self-neglect there stands out from approaches in other jurisdictions. This affects definitions, interventions, policy responses, and the degree of attention devoted to self-neglect, as will become apparent from this report.

The literature does convey a strong sense (see, for example, Blagodatny et al, 2007) that cases of self-neglect present management difficulties and ethical challenges. This sense also emerged from the focus group and workshops. Self-neglect for the focus group participants caused anxiety and difficulty. They worried about those who would not engage with services. Thus:

> 'Then the other issue is those who are behaving in a way that is causing us great anxiety around self-neglect, or engaging in behaviours that's putting them at risk.' (Focus group participant)

> 'I think it's a real difficult subject really where people are declining services. I'm not convinced 100 per cent our coroner … will have heard about the personalisation agenda and independence, choice and control and I think he will, without a doubt, see this [a case where someone had been self-neglecting and had died] as a failing of services and we should have acted. The man had capacity, you know. He was given all assistance but basically he said, "look, I don't want you in my house; I don't want anything that you could offer me; I'm

quite happy living in the manner in which I want to live and go away" … I think it's a real difficult issue.' (Focus group participant)

Workshop participants and key informants reported that several Boards were currently conducting serious case reviews where self-neglect was a central feature. While interagency learning and action plans arising from individual reviews are embedded within Board quality enhancement processes, there does not appear to have been any attempt so far to collate and extract common themes from all reviews in cases of self-neglect. While not without difficulties, for example, in tracking down all the serious case reviews that have been written, useful learning could be extracted from periodic analyses of completed serious case reviews, along the lines of completed meta-reviews in respect of children who have died or suffered serious injury (see, for example, Reder et al, 1993; Sinclair and Bullock, 2002).

Overall, this was felt to be a difficult subject area on which to write policies and procedures, given the difficulty of defining exactly what self-neglect is, and how it manifests. As one workshop participant commented, it is "a foggy mass of mess".

2 Conceptualising self-neglect

2.1 Defining self-neglect

It quickly became clear that the body of research identified for this review draws on a range of definitions of self-neglect which differ among themselves to a greater or lesser degree. In part this reflects the fact that some papers focus on particular aspects of self-neglect, such as hoarding, animal collecting or non-compliance with medical services, and thus deliberately exclude other considerations. For example, Lauder et al (2009) suggest that hoarding and squalor may be features of distinct sub-groups within those described as self-neglecting. Alternatively, others treat self-neglect as only a sub-category of some overarching phenomenon such as 'risky behaviour' (Nikolova et al, 2004). Self-neglect is thus a category that in practice can be broken down into a number of different sub-phenomena, or itself viewed as only a sub-phenomenon of other categories. The problem goes beyond this, however, as it is apparent that there is no consistent definition of self-neglect itself to inform the literature (Gunstone, 2003; Dyer et al, 2007a, p 14; Kutame, 2007, p 8; Fulmer, 2008; Paveza et al, 2008, p S274; Pavlou and Lachs, 2008; Spensley, 2008, p 44; Griebling, 2010). As O'Brien et al (2000, p 2) put it, 'the definition of self-abuse varies from study to study and country to country, which makes interpreting this body of work more difficult'. This makes it a challenge to 'generate appropriate guidelines for the detection and intervention of neglect cases' (Fulmer, 2008, p S242). Gunstone (2003) and Paveza et al (2008) both illustrate how clinicians vary in their recognition of self-neglect, while Kutame (2007) even sees the term self-neglect itself as problematic since it locates the problem in the individual rather than in services or their environment.

The distinction between countries appears to have a major influence on how self-neglect is understood. McDermott et al (2009), writing in the Australian context, highlight the differences in how self-neglect is perceived in the US and the UK. They suggest that in Australia self-neglect as a general category is not really used. Rather, lack of self-care, hoarding/collecting and squalor are treated as separate phenomena. Of even greater significance, however, is that:

> … in many US states, self-neglect is categorised as a type of elder abuse that professionals are mandated to report to their local Adult Protective Service organisation for investigation. (McDermott et al, 2009, p 247)

In the UK and Australia, meanwhile, there is no mandatory reporting, and self-neglect is not categorised as part of abuse in the same way as it is in the US. The findings of the present review bear out that this difference has significant consequences for the literature emerging from each national legislative context.[1] Not only has the greater visibility of self-neglect on the agenda of services in the US given rise to a much larger body of research into the phenomenon, but most, although not all, of these studies have taken – either explicitly or implicitly – statute or service definitions as their starting point. This often determines the definitions of self-neglect that serve as the starting point for the research. Furthermore, even where this is not intentionally the case, it still affects how studies are carried out. Because so many identify their population of interest from adult protection services casework, in effect it becomes

inevitable that these definitions will come to permeate the US literature. Equally, the definitional diversity makes it difficult to generalise from one country to another in terms of identifying prevalence (Lauder et al, 2005b).

There is no absolute consistency in the statute definitions. Daly and Jogerst's (2003) study of statute definitions of abuse and neglect across the 50 states of the US calls attention to the inconsistencies to which this can give rise, and the obstacles this presents to the advance of research knowledge. They report that:

> Ten state statutes have self-neglect definitions independent of other definitions. The primary term defined is "self-neglect" for 8 of the statutes, "inability to manage his personal care" for another state, and one did not have a term, just a definition. The concept of self-neglect was found in 21 of the APS (adult protection services) state statutes in the definition of neglect. The actual term "self-neglect" was not used in the neglect definitions. The concept of self-neglect was also found in the three of the ANOS[2] definitions again without the use of the term "self-neglect". (Daly and Jogerst, 2003, p 47)

They conclude that:

> It is unlikely that legislation for the 50 states and District of Columbia would be implemented to change the statutes definitions of elder abuse but it is possible to develop a list of definitions that can be used as model definitions for researchers, practitioners, and for future policy changes. (2003, p 54)

In practice, many of the US studies place the individual's 'health and safety' or 'basic needs' at the core of self-neglect. Hence, for example, Bergeron writes of self-neglect as a situation of 'unmet basic living and medical needs' (2006, p 85) where there is no perpetrator; Blondell similarly as unmet 'basic needs', 'safety needs' and 'psychosocial needs' (2000, p 61); Gill as 'an ill-defined syndrome characterized by the inability to meet one's basic needs to an extent that it poses a threat to personal health and safety' (2009, p 570); Buckingham et al (2008, p 5) as 'the inability to care for oneself or take the necessary actions to avoid self-harm'; Payne and Gainey (2005, p 23) as 'entail[ing] situations in which the individual fails to provide care for himself or herself in such a way that one's health or physical well-being may decline precipitously'; and Choi et al (2009, p 172) as the 'vulnerable adult's action or inaction that results in his or her essential needs not being met, or physical or mental inability or refusal to adequately attend his or her needs'. Lachs (2008, p 757), while not explicitly defining self-neglect, emphasises its implications for health, arguing that 'by definition, self-neglecters (particularly those who really excel at it, thereby attracting the attention of the local APS office), represent the most extreme examples of medical non-adherence'. According to Aung et al:

> The operational definition of self-neglect used by the APS workers in Harris County, Texas is the failure to provide for one's self the goods or services, including medical services, which are necessary to avoid physical or emotional harm or pain. (2007, p 67)

Given the extensive body of work in this review that originates from Texas, this definition thus exerts considerable influence over many of the findings here. Finally, Bozinovski (2000, p 38) cites a definition developed by the Self-Neglect Committee of the National Association of Adult Protective Services Administrators (NAAPSA) as a composite of those from 28 states:

> Self-neglect is the result of an adult's inability, due to physical and/or mental impairments or diminished capacity, to perform essential self-care tasks including: providing essential food, clothing, shelter, and medical care; obtaining goods and services necessary to maintain physical health, mental health, emotional well-being and general safety; and/or managing financial affairs (NAAPSA, 1991, p 3).

'Health' and 'basic needs' can here be seen to be key concepts in enabling adult protection services workers and others with mandatory reporting obligations to negotiate their role in cases of suspected self-neglect.

Left unstated in the examples quoted above is the complexity introduced in formulations such as the following:

> Self-neglect is recognized as the *failure* or *unwillingness* to provide oneself with the basic care needs required to maintain health. (Burnett et al, 2007a, p 36; emphasis added)

This is where most controversy arises; Dyer et al (2006a), having explored the working definitions of self-neglect held by adult protection services workers, reported that 56 per cent felt that it was inability to self-care, 8 per cent unwillingness and 36 per cent either one or other. Payne and Gainey (2005) cite a National Center on Elder Abuse declaration (2004) which, having defined self-neglect as 'the behavior of an elderly person that threatens his/her own health or safety', states that such a definition:

> ... excludes a situation in which a mentally competent older person, who understands the consequences of his/her decisions, makes a conscious and voluntary decision to engage in acts that threaten his/her health or safety as a matter of personal choice. (Payne and Gainey, 2005, p 24)

Where exactly the boundaries fall between inability and unwillingness, and how to decide the extent of the competence of the individual concerned, is at the heart of efforts to tackle the problem, and is an issue to which we will return.

2.2 Different manifestations of self-neglect

Self-neglect, the term most commonly used across the literature, covers a multitude of manifestations, some of which may at first sight seem to be only tenuously related to each other. Although most of the references in the review used the general category 'self-neglect' to cover a variety of different behaviours, some focused on more specific sub-categories. For example, 14 specifically picked out living in squalor as a phenomenon of interest, while 8 homed in on hoarding. Besides these, three

dealt with hoarding of animals as a phenomenon in itself (Boat and Knight, 2001; Arluke et al, 2002; Nathanson, 2009), while others looked at self-neglect as a lack of self-care, which could have a number of meanings from lack of attention to personal hygiene to non-conformity with medical care plans. In other papers, self-neglect was not clearly distinguished from neglect or abuse by others.

At times the diversity of manifestations that are characterised as self-neglect, coupled with the ethical and practical difficulties involved in deciding when someone counts as 'self-neglecting', seem almost bewildering. People may display one behaviour thought to be typical of self-neglect while not showing others; for example, Lauder et al (2009) found that some people who happily live in squalor may be fastidious about maintaining their own personal hygiene. This raises the question of what distinguishes self-neglect *as* self-neglect. Naik et al attempt to answer:

> A predicate state of vulnerability from diminished capacity for self-care and self-protection (SC&P) may be a common denominator of the various clinical phenotypes of chronic self-neglect, and incapacity for SC&P can also expose elderly people to numerous forms of abuse, medical morbidity, placement in long-term care, and even death. (2008c, p S266)

What determines or counts as that 'predicate state of vulnerability', however, is complex, as the rest of this review will show.

2.3   Diogenes syndrome

It was suggested (McDermott et al, 2009) that in the UK the psychiatric diagnosis of Diogenes syndrome serves as a framework within which to group the sometimes disparate phenomena that are characterised as self-neglect. The review findings do not bear out the suggestion that such an approach is particularly British; three papers on Diogenes syndrome reported here originated from England (Halliday et al, 2000; Ngeh, 2000; Al-Adwani and Nabi, 2001), but others came from Brazil (Fontenelle, 2008), Spain (Galvez-Andres et al, 2007), France (Lebert, 2005), Colombia (Reyes-Ortiz, 2001), Canada (Montero-Odasso et al, 2005) and the US (Greve et al, 2004, 2007; Dick, 2006; Blagodatny et al, 2007; Donnelly et al, 2008). While many other papers mentioned the Diogenes syndrome diagnosis in introductory discussions of self-neglect, these authors gave it a central role. The diagnosis was first established by Clarke et al in 1975, and may apply to elderly people who present with a filthy personal appearance, dirty or insanitary home environments and/or the hoarding of rubbish, and who refuse interventions from others. None of those described in the original case studies suffered from financial difficulties that might partially account for their situation. This description has historically played a significant part in bringing self-neglect to the attention of health professionals (Poythress et al, 2007) and provides a ready-made definition of the phenomenon for research of a psychiatric bent, although many of these papers in fact quibble with one or other element of the original description. Halliday et al (2000), for example, challenge the use of Diogenes syndrome to qualify those who live in squalor, suggesting that few of the cases they studied conformed to the full criteria of that label. They highlight that there may be differences between squalor of physical aetiology and squalor of psychiatric aetiology

and therefore that the diversity of this group was such that applying the diagnosis to all of them served more to confuse than clarify their condition. They conclude that:

> … squalor may be treated best as a state associated with, or a consequence of, a range of physical and mental disorders which requires careful assessment and treatment, rather than as a rare syndrome due to reclusiveness or an eccentric personality.[…] The focus on domestic squalor being a function of Diogenes syndrome may have diverted attention from squalor as an important public-health problem in itself. Our results suggest that "Diogenes syndrome" should be regarded as a term of historical interest rather than of clinical utility. (Halliday et al, 2000, p 886)

Fontenelle (2008) similarly questions whether hoarding should be seen as core to Diogenes syndrome, showing that it is a feature of conditions that frequently co-present with it (schizophrenia, OCD [obsessive-compulsive disorder], dementia, anorexia, etc) and calling for in-depth assessment to ensure that the underlying complaint is accurately identified. Montero-Odasso et al (2005), in contrast, argue that hoarding is a useful indicator of possible Diogenes syndrome and should lead the clinician to consider such a diagnosis.

Other authors link the Diogenes syndrome diagnosis to Capgras syndrome (Al-Adwani and Nabi, 2001; Donnelly et al, 2008), fronto-temporal dementia (Lebert, 2005; Galvez-Andres et al, 2007), (possibly sub-clinical) personality disorder (Reyes-Ortiz, 2001; Greve et al, 2004), personality factors and psychosocial stressors, linked with the effects of ageing and possible dementia (Ngeh, 2000), or various combinations of the foregoing (Dick, 2006; Blagodatny et al, 2007). Greve et al accurately sum up the state of evidence emerging from this current work with their conclusion that:

> … the behavioral presentation of Diogenes syndrome is etiologically complex and psychiatric and/or neurological co-morbidities may be, but are not necessarily, present. (2007, p 705)

Equally, there is no arguing with their point that:

> … whether or not one believes in the existence of a specific behavioral phenomenon referred to as Diogenes syndrome, the behavioral presentation reflects a significant functional problem contributing to increased morbidity and mortality and may reflect the action of one or several mechanisms including personality disorder and dementia. (2007, p 704)

2.4   Constructionist critiques

The foregoing definitions for the most part are effective in orienting practitioners towards a given problem in a relatively straightforward manner that can serve as a foundation for action. A minority of authors, however, have argued for the consideration of more complex perspectives on self-neglect, and their views bear examination here. Seven papers in particular, written by authors whose outlook could loosely be termed 'constructionist', were particularly concerned to unsettle the

consensus, which – they claim – pays insufficient attention to the extent to which policy priorities and broader cultural influences have shaped how researchers view self-neglect.

William Lauder and his co-workers have been strong proponents of this view, and of those included in this review three of their papers put the case for it with particular emphasis. They start from the position that:

> … the disease model of self-neglect has been the dominant social construction but challenges to the disease model of self-neglect have recently emerged in the literature[…]. This challenge raises doubts about a simplistic cause–effect relationship in which a disease or groups of diseases cause a discrete medical syndrome. Instead it is suggested that self-neglect may be a social construct influenced by social, cultural and professional values. (Lauder et al, 2001, p 601)

Lauder and Orem (2001) too raise the question of the degree to which the definition of self-neglect lies in the interplay between culture, context and the individual, implying that it may often be a value judgement as opposed to an objective phenomenon. Then, a 2002 paper by Lauder et al presents an overview of a number of sociological and psychological theories that can be brought to bear on self-neglect (Lauder et al, 2002a); here constructionism is nuanced by other theoretical approaches including personal construct theory, structural-functionalism, interactionism and attribution theory. However, while the authors thoughtfully show how each theory brings strengths and weaknesses to bear on self-neglect, they devote less attention to how one might attempt to integrate them together. This risks leaving the practitioner in search of guidance with a bewildering range of choices.

As this 2002 paper illustrates, constructionist positions cannot be neatly marked out from social and psychological theories of self-neglect, but rather tend to represent a special case of these latter. Thus Bozinovski sets out to develop a social psychological model of self-neglect in older people, with considerable success, but what marks her approach out as constructionist are the following conclusions:

> Self-neglect is not an objective, measurable entity or process. Rather, self-neglect is a complex, ambiguous, multifaceted social construction. At the macro-level, interest groups are in the process of constructing self-neglect as a social problem. At the micro-level, older persons labeled "self-neglecting", and those they interact with, are constructing self-neglect as well. (2000, p 52)

She also suggests that:

> … no research has truly answered the question of why older persons neglect themselves, perhaps because the answer lies not so much in external conditions such as living arrangements, but in the perceptual realm as well. The problem is one of differential perceptions on the part of persons labeled self-neglecters and their labelers. (2000, p 38)

A later paper by Lauder and colleagues argues that cultural norms play a strong role in marking out a context-specific view of self-neglect, identifying in the UK cultural context two factors – a preoccupation with hygiene and sanitation and a cultural tolerance of eccentricity – as contributing to an 'ambivalent and contrary attitude towards those who self-neglect' (Lauder et al, 2005b, p 47). The paper links professional understandings of self-neglect explicitly to value positions embedded within professional cultures, demonstrating that nurses and social workers, for example, prioritise different patient characteristics in their judgements about self-neglect, and identifying how Kantian and utilitarian ethics support sometimes competing principles of autonomy and protection in framing interventions.

McDermott (2008) also questions the role that professional definitions play in creating the object with which they aim to work. Focusing on squalor, she draws attention to the use of the term 'hoarding' to refer to the accumulation of possessions that are perceived *by professionals* as having no value, and that of 'collecting' when they are perceived as having value. The significant point for her is that the judgement is made by professionals. Beyond this, she also draws attention to how cases involving squalor/hoarding tend to be given to social care workers, while lack of self-care tends to be led by health professionals. She challenges the value of considering the 'different' phenomena together as one.

Lee (2007) also shows how perceptions of self-neglect may vary markedly according to culture, in his study of how Korean older people perceive both self-neglect and abuse, and the negative associations they may place on seeking formal help from institutions.

Phillipson's (2000) prevalence survey may not at first sight seem to belong in this company, as the very exercise of carrying out such a study implies the concrete existence of what is being measured. However, the emphasis that he places on the possible significance of fear and uncertainty over guarantees of care and support, in giving rise to elder self-neglect, suggests the extent to which broader cultural phenomena may work to manufacture conditions such as self-neglect in the individual. For Phillipson, social exclusion is a huge force in compounding powerlessness and rejection in the individual's life history. In any event, constructionist perspectives are not by definition seeking to deny that self-neglect exists, but merely to demonstrate how:

> ... understanding of self-neglect, and how to respond to it, are influenced by values and meanings that are the product of social and cultural practices and beliefs. (Lauder et al, 2005b, p 47)

2.5　Who experiences self-neglect?

The literature makes plain that self-neglect is overwhelmingly seen as a problem of older adults, a 'geriatric syndrome' in the words of Pavlou and Lachs (2006a, p 831). Of the 155 references included within the review, 117 dealt with self-neglect in older adults. Furthermore, of those that did not focus exclusively on older adults, there was nevertheless often a strong predominance of this group in what was discussed. Mental illness in younger adults constituted some of the remaining cases, whether

discussed in general terms (Gunstone, 2003), or with reference to fronto-temporal dementia (Galvez-Andres et al, 2007; Bedoin et al, 2009) or schizophrenia (Steinert et al, 2005). Indeed, Pavlou and Lachs (2006b) note that younger people who are self-neglecting show an increased likelihood of having a mental disorder (see also Iris et al, 2010). They also note in passing that it is difficult to know whether self-neglect is more common in older adults than in younger, or whether it is simply that older adults are less able to manage challenges of life and therefore more likely to come to the attention of services. As will be seen later in the discussion of assessment and intervention, one emerging theme in the literature is that older age may represent a time when behaviours that earlier had in some way been functional for an individual, such as collecting, now become dysfunctional as the person becomes less able to manage their consequences.

The emphasis on older people was slightly less evident in cases of squalor or hoarding (either of objects or animals). Lauder et al (2005c, 2009), Nathanson (2009), McDermott (2008), Lahera et al (2006), Snowdon et al (2007), Snowdon and Halliday (2009), Arluke et al (2002) and Halliday et al (2000) are among those who deal with these phenomena in younger as well as older adults. Lauder and colleagues (2005c, 2009) in particular are at pains to point out the diversity of presentations that is sometimes masked by a focus on elderly self-neglect, highlighting that a number of younger adults also appear in their sample, including a number of single mothers living in squalor. Their samples in these studies are small, and certainly it would be premature to draw broad conclusions about the make-up of self-neglecting populations on this basis; on the other hand, these clients were identified by social care and voluntary sector workers and therefore likely to be partly representative of at least some of the challenges they face on the frontline from day to day. The authors conclude that their findings:

> ... further challenge [...] existing definitions of self-neglect and highlight [...] the importance of further work focused on clarifying the concept and the identification of clusters and patterns within cases of self-neglect. (Lauder et al, 2005c, p 320)

McDermott (2008) is another who has questioned whether such phenomena really are so much more common in older than younger people, or whether older people are simply less empowered in resisting negative judgements by others. Gibbons (2007) too raises the possibility that self-neglect is not so much related to ageing as to complex health and social circumstances, and an individual's ability and willingness to address them. Given Reyes-Ortiz's (2006) suggestion that an early, preventive approach might bear fruit, it is perhaps regrettable that so little attention has been paid to younger people.

2.6   Operational definitions held by those working with self-neglect

A limited number of papers, aware of the unsatisfactory nature of many official definitions of self-neglect, set out to explore how those responsible for working with people who self-neglect formed their own understandings of the phenomenon through their day-to-day practice. They took a variety of different approaches in doing so.

One of the most intriguing, because of the scale of the project, was a study by Brown et al (2009) which sought to identify priorities for the development of research into self-neglect. Definitions of the phenomenon were only one category among many; indeed, a total of 273 ideas were submitted to the research team through a process of online generation of ideas among a community of professionals. Content analysis and a process of sorting and rating are ongoing, and are ultimately intended to lead to a series of 'concept maps' of self-neglect.

Iris et al (2010) also used concept mapping. This study sought to develop a hierarchical conceptual model of the elements of self-neglect based on perceptions of professionals working with older people. The model examines personal, environmental and social risk factors alongside self-care deficits. Two broad domains emerged: physical and psychosocial aspects of self-neglect, encompassing physical and mental health, personal endangerment and social networks; and environmental aspects, including physical living conditions, personal living conditions and financial issues. Their mean importance placed clusters of features associated with self-neglect in an order of importance:

1. Physical living conditions (denoting inability to care for self or environment)
2. Mental health
3. Financial issues
4. Personal living conditions (linked to the notion of lifestyle choice)
5. Physical health
6. Social network
7. Personal endangerment

The importance accorded to mental health may imply a leaning to the 'inability to care for self' explanatory model as opposed to the 'lifestyle choice' model. Put another way, self-neglect behaviour arises from cognitive impairment or depression. The prominence of financial issues is seen as a risk factor rather than an indicator of self-neglect, the authors speculating that lack of care may arise from lack of funds. The focus on social networks raises a chicken and egg issue since it is difficult to know whether isolation is self-imposed or situational.

Thus, Iris et al (2010) located self-neglect within the notion of population shift and demographic trends that have both physical/medical and social sources. They comment that:

> As more people live to the later stages of life with chronic, degenerative physical and cognitive diseases such as Alzheimer's disease or congestive heart failure, we are likely to see an increase in the number of older adults who can no longer meet their personal and instrumental needs or take care of their homes and properties. Other more socially grounded factors include older adults outliving their social support systems, increased risk of poverty associated with longevity, lack of adequate transportation options so that access to physicians and other health care providers is limited as well as difficult, and changing demographic characteristics of local communities, with the result that many older adults feel isolated within their own homes and lack connections with newer residents. (2010, p 1)

Another intriguing approach was that taken by Buckingham et al (2008), who sought to pick out the cues and knowledge structures used in practice by clinicians to make judgements of risk with four presenting conditions, among which was self-neglect. To this end they carried out semi-structured interviews with 46 practitioners from different mental health-related disciplines, and applied content analysis to construct 'mind maps' of the basis of their risk-assessment knowledge. A finding that was particular to self-neglect (as opposed to the other conditions surveyed – suicide, self-harm and harm to others) was the lack of emphasis these practitioners placed on previous relevant history (either of the individual or of their family) in arriving at their decisions. It was also noteworthy that they gave minimal consideration to motives or intentions relevant to self-neglect; rather, the assessment was heavily dependent on the client's current circumstances and what could be observed directly of their appearance and surroundings. This contrasted significantly with the other three situations, and the authors speculate that this may indicate that self-neglect assessment is accorded a lower priority, or at least less urgency. They conclude that:

> The lack of priority placed on verbal content, body language, feelings, emotions, or any assessment of the patients' mental state (apart from depression) indicates assessors do not see self-neglect as a willed behaviour, comparable to other kinds of self-harm. The diminished significance of self-neglect compared to other risks suggests it is an area in which cognitive modeling needs to be more prescriptive from the outset. (Buckingham et al, 2008, pp 15–16)

In contrast, Lauder et al (2006) presented registered nurses with vignettes to investigate their judgements of capacity in self-neglect, and found that as much as 88 per cent of the variance could be accounted for by their clients' mental health status. Unlike Buckingham et al's (2008) conclusion that practitioners were heavily dependent on direct observations of their current situation and appearance, Lauder et al write that, besides mental health status,

> ... almost all other patients' household and personal hygiene features play little part in judgement formation. (2006, p 285)

They go on to suggest that:

> ... matters around hygiene and squalor are the essence of self-neglect, however it is understood, and for nurses not to utilize these in their judgements may highlight how complex and puzzling nurses find this phenomenon. When they find themselves facing self-neglect they resort to tried and tested cognitive schemata. (2006, p 285)

Where the two papers find themselves in agreement is in calling for more education on self-neglect. The differences in these findings may reflect the different samples studied (a range of mental health practitioners in the first, compared with registered nurses in the second), differences in national training and practice (Buckingham et al, 2008, carried out their research in England, while Lauder et al, 2006, report on nurses in Ohio, US) or other factors not immediately obvious.

Another study that used vignette presentations was that by Kane and Green (2009). Elder self-neglect could be identified among the features described in the vignettes, which were given to a sample of human services students. Only about a third of the students considered that self-neglect might be occurring, while half considered neglect. The authors suggest that this indicates the need to give education on neglect a higher priority in the third-level curriculum; they also found that 'self-enhancement' – an exercise whereby the student imagines themselves in old age – was effective in partially overcoming tendencies towards ageism, and suggest that this could play a part in this kind of educational intervention. However, the geographical limitation of the study to one US college and the subsuming of students from different disciplines under the catch-all 'human services' raises doubts about how far this paper can be generalised.

Lauder et al (2001) used a factorial survey format for vignette presentation in another study on nurses' and nursing students' decision making on self-neglect. This time, however, their six-variable model was only able to account for 21.4 per cent of the variance in responses. Psychiatric nurses, general nurses and student nurses here did not differ significantly in their mean ratings of self-neglect, and were all found to rate patients as choosing to lead many aspects of their lifestyle (general nurses were slightly more likely to do so). The authors wonder whether the statistical limitations of their vignette measures may partly account for their inability to account for more of the variance, but conclude that the study 'again illustrates the lack of conceptual clarity about self-neglect' (2001, p 607).

More in-depth qualitative investigations were carried out by Dyer et al (2006a), Gunstone (2003) and Lauder et al (2005c). As already noted, Dyer et al established that 56 per cent of adult protection services workers interviewed felt that self-neglect was an inability to care for oneself, 8 per cent an unwillingness to care for oneself and 36 per cent felt that it could be either of these. When evaluating possible neglect, they focused most on derangement of the environment, on lack of hygiene and health-related factors and on food stores and cognition. Workers were more 'comfortable validating self-neglect, but were concerned about falsely identifying a caregiver as neglectful' (Dyer et al, 2006a, p 6). However, ultimately the maxim 'we know it when we see it' (Dyer et al, 2006a, p 8) is what best sums up their reports, and the main lessons the paper draws from the study are the importance of home visits and non-reliance on proxy reports, as well as the need for an objective screening instrument (see later).

In Britain, Gunstone similarly set out to explore mental health workers' own working definitions of self-neglect, and found that they were far from simple. Gunstone went on to use thematic content analysis, and the themes which emerged were: the workers' tolerance to self-neglect; policies, procedures and legislation; definitions of self-neglect; and risk assessment (2003, p 289). The first of these, tolerance, was recognised to settle at higher or lower thresholds through their careers as they gained experience or became de-sensitised, something with which they dealt through supervision and team discussions, referring to policies, and conducting as thorough an assessment as possible. On the second, the policies, they made specific mention of the Care Programme Approach (CPA) and the Mental Health Act 1983, but it appeared that, on the one hand, the workers lacked detailed knowledge of

the full range of different applicable policies, but, on the other, detailed guidance on self-neglect was anyway lacking in those policies. The workers themselves drew attention to the lack of a satisfactory definition in existing guidance. On the third, definitions, failure to eat/drink adequately, to maintain personal care, to maintain home environment, to manage finances, to maintain social contact, to comply with treatment and to protect themselves from abuse or exploitation were all listed as possible indicators (2003, p 291). On the fourth, risk assessment was valued highly, to some extent in contrast to standardised assessment tools, which were felt to suffer from an inappropriate 'one size fits all' approach. Practitioners tried to gather information from as many sources as possible and make extensive observations to facilitate their judgements. Overall, one of the most consistent characterisations of all these aspects of self-neglect was as 'grey areas', where it was acknowledged that there was a great deal of scope for ambiguity, vagueness and individual variation.

Although uncertainty does not emerge as such a central theme in Lauder et al's (2005c) study of how housing officers, social care workers and environmental health officials work with self-neglect in Britain, the partial nature of their different perspectives came across clearly:

> Data revealed the limited knowledge which professions often had of each other's roles and none had a "comprehensive overview" of the nature of the problem and the possible different interventions. Liaison between professions was often ad hoc and dependent on the commitment of individual workers, rather than generally established procedures. Even the relatively co-ordinated mental health intervention pathway did not fully include housing and environmental health agencies. (Lauder et al, 2005c, pp 322–3)

Although individual workers frequently made efforts to overcome the limitations of their roles, particularly when these might be expected to place them in an adversarial relationship with the self-neglecting person, it was plain that these roles did much to determine how they approached the problem. One of the biggest differences in this respect was whether a psychiatric diagnosis had been established, as this led to a much more thorough and sympathetic assessment and intervention. Overall the study, drawing on the experiences of these interviewees, puts the case for recognition of the diversity in self-neglect, finding significant differences in how it emerges (whether as a result of long-standing patterns over time or of sudden triggering events) and between neglect of one's own personal care and that of one's surroundings, which sometimes seemed to be independent of each other.

Finally, Harbison et al (2004) also carried out interviews and focus groups that touched on the question of definition, arriving at the conclusion that the social context inevitably shapes workers' perspectives. They suggest that in rural areas of Canada these may be affected by the store set by independence and self-reliance, and a consequent distrust of institutional care and higher levels of tolerance in the community. Unfortunately, the paper's broad focus on abuse and neglect alongside self-neglect means that little space is devoted to expanding on these themes.

Looking at the findings of these studies in the round, it is clear that while professionals seem in large part to have developed their own heuristics and

benchmarks for what they are talking about when they discuss self-neglect, there is a considerable amount of uncertainty about the precise nature of the concept. This may be less marked in the US, where mandatory reporting laws necessitate greater familiarity with definitions and requirements; nevertheless, disagreement is found among adult protection services workers even there. In Britain, those who work with self-neglect are often open about the 'grey areas' they find so characteristic of the area. Vignette, interview and focus group studies reveal a picture of workers getting by as best they can with the features of self-neglect that stand out as most evident and salient to them, while all the time aware of the fundamental ambiguity of many of the situations that present to them as possible self-neglect.

2.7   Public perceptions of self-neglect

Very few studies specifically set out to focus on this; one might surmise that – given the ongoing debate over definitions of self-neglect among professional workers and researchers – investigating public views has not so far been a high priority. However, it has been argued that garnering some measure of public perceptions of self-neglect is of significant importance to inform efforts to raise public awareness of safeguarding (Dakin and Pearlmutter, 2009). Be this as it may, the research into this topic is exclusively from the US and for the most part seems to be of limited generalisability.

Dakin and Pearlmutter (2009) gathered focus groups of women from different ethnic backgrounds and socioeconomic status (SES). Their discussions mostly focused on definitions of elder mistreatment, and as they report that only the high SES Caucasian group viewed self-neglect as part of elder maltreatment (2009, p 28) – in contrast with the definitions to be found in official US legislation – self-neglect played only a minor part. What they did find was that all focus groups favoured involuntary protection over autonomy in the vignette with which they were presented, and they suggest that public education may be needed to combat ageist public attitudes behind such thinking. Differences in attitudes towards the elderly could be found between the different ethnic groups. Filippo et al (2007), likewise, found cultural and generational cohort differences in responses when they presented recruits with statements about self-neglect and asked them to agree or disagree. Both these studies, however, are limited by their use of convenience samples; in the first study, from women already involved in social programmes (Dakin and Pearlmutter, 2009, pp 52–3), in the second, from students at night classes, attendees at fairs and attendees at senior centres who were willing to respond to a survey (Filippo et al, 2007, p 220). It also remains unclear whether their findings might apply to the British context, something that can also be said of the third study that approached this topic (Lee, 2007). Lee studied the perceptions of Korean immigrants in his doctoral thesis, and reported that respondents showed less sensitivity to problems of self-neglect, neglect and mistreatment, and had a negative attitude to formal help seeking. He also reiterates the importance of considering these issues to inform prevention and intervention strategies in different cultural groups.

2.8   Definitions by people who self-neglect

Harbison et al (2004) point out that the definitions of self-neglect appearing in the research very rarely emerge from the older people themselves. It is even more rare that people engaging in self-neglect, of all ages, are directly asked for their perspectives on what they are going through. However, some scholars have attempted to tackle this fascinating question.

Gibbons (2007) describes how she used a phenomenological interview approach with a sample of people showing self-neglect. She classifies them as 'challenging patients' who – while they 'pose a potential risk to themselves because of non-adherence and inadequate self-care practices' and may have chronic mental or physical disease – are in a condition that falls short of full-blown severe self-neglect (Gibbons, 2007, p 194). A range of themes emerges from what they have to say, any of which might shape a given case of self-neglect. In these interviews, these were changes requiring new coping skills (whether these are physical change, social change, personal change, cognitive change), one's philosophy of life and death (in the form of a sense of personal control, one's fears and the need to protect oneself), cultural influences (especially with regard to medical culture), social influences (community, financial and other social influences) and the influence of family, particularly spouses. Gibbons suggests that this validates her theory of self-neglect (see later), and:

> ... confirmed that self-neglect is not as much related to aging as it is to complex health and social circumstances and to an individual's ability and willingness to address these. (2007, p 199)

Alongside capacity for self-care, norms and motivations are here seen as no less integral to the 'many variants of this phenomenon' (Gibbons, 2007, p 199).

Bozinovski, whose constructionist, grounded theory-based study drew on interviews with 20 adult protection servicesS caseworkers and 15 adult protection services worker supervisors as well as 30 elderly self-neglecting adult protection services clients, also paid attention to some of the psychological factors that could bring about situations of self-neglect. She states that:

> ... although self-neglect is the typical adult protective services case, there is no typical self-neglect case ... (2000, p 38)

but was able to draw some conclusions about the nature of self-neglect. She identified 'maintaining continuity' as a central theme in the interviews, which is broken down into concern to 'preserve/protect the self' from threats such as interpersonal problems or the intervention strategies of adult protection services workers, and to 'maintain customary control'. Individuals may react by attempting to construct or present their personal identities in ways that make sense in the light of these concerns, or by exercising preserved control over those aspects of their lives which they can still affect. However, such striving for continuity may become dysfunctional as their capacity starts to fail.

Bozinovski suggests that insufficient research attention is paid to the extent to which the different perceptions held by those labelled as self-neglecting and those doing the labelling complicate research into the causes of self-neglect (2000, p 38).

Efforts such as this, and that of Gibbons (2007), make a contribution in showing how diverse the perspectives of older people who self-neglect may be, which is essential to grasp if the phenomenon is to be better understood.

Kutame (2007), meanwhile, carried out interviews with 12 older adults engaging in self-neglect for her doctoral thesis. As with Bozinovski (2000), her interviewees were identified by adult protection services workers as suitable candidates to participate, that could have implications for the representativeness of the study; certainly it seems probable that those selected were from the less severe end of the spectrum. They themselves in no way:

> ... "interpret[ed]" their situation as self-neglect, although participants talked about chronic health issues, pain, weakness, inadequate resources, and lack of supportive network. (Kutame, 2007, p 169)

Interviewees saw their difficulties in terms of these categories, which quite clearly locate the problems outside of their own control. However, Kutame (2007) also identified a number of positive themes that they apply to their situation, and which she urges should be taken into account. Pride in self-sufficiency, a sense of connectedness to the places and things in their surroundings, and coping mechanisms informed by religious faith and prayer, come through strongly in much of what they have to say. Such values, which lay considerable importance on independence, are often coupled with a sense of mistrust of many healthcare professionals and a tendency to non-compliance with medical recommendations. Kutame offers insight into their perceptions of self-neglect in the following statement:

> When asked what they would say to someone who might see their unmet needs, like not making necessary repairs on the house, not having enough money to buy food, etc, the study participants responded that they "take care" of themselves, do their "best to make ends meet", prioritize and "let other things go". (2007, p 171)

The picture painted is one where the perceptions of the individuals concerned and the professionals who seek to intervene with them are at odds. This leads Kutame (2007) to criticise the very term 'self-neglect' for what she sees as its tendency to divert attention from service failings and ecological problems by casting aspersions on the individual, although she does not suggest other terms that might provide viable alternatives. The main argument of the thesis is that self-neglect is a complex phenomenon and that greater priority needs to be given to eliciting an individual's unique circumstances and perceptions of their situation as a part of assessment and intervention. This, she suggests, would go some way to strengthening individual older adults, their families and communities, and addressing the failings in service interventions and governmental action in support of the vulnerable elderly population. Such a recommendation might be described as a strengths-based approach towards elderly self-neglect.

Kutame's focus (2007) on service shortcomings resonates with an empowerment and social model perspective, which emerges through some papers that highlight community resources. Thus, Day and Leahy-Warren (2008b), for instance, stress that some older people who self-neglect have poor social support networks and poor services.

Lauder et al (2009) deliberately set out to explore manifestations of self-neglect that seldom become the focus of research scrutiny, and in doing so challenged existing consensus on its definition. They examined:

> … self-neglect from the standpoint of a group of people regarded as self-neglecting, but who differed in significant respects to stereotypical cases. Their lifestyle was similar to classic cases of self-neglect in some respects, but they differed in the extent to which they were younger, maintained social contacts and were in close contact with health, social or voluntary services. These related cases suggest that lifestyles and behaviours which we classify as self-neglect are wider and less clear-cut than previously suggested. Co-morbidity is an ever present feature of self-neglect in all its presentations, although this appears to be a much wider issue than the presence of mental illness. (2009, p 452)

Those interviewed here were younger people, in whom self-neglect takes different forms from those commonly noted in older adults. The features most noted by Lauder and his co-authors amounted to:

> … a picture of chaotic lifestyles, attempts at reform, spirals of substance dependency and the inability of statutory services to cope with people on such trajectories. (2009, p 450)

While they comment on the 'broader spectrum of presentations' (2009, p 453) in their study than is acknowledged in the existing literature, housing problems, squalor and poor self-care are recurrent here too. However, they point out that:

> … this group differed from many existing studies of self-neglect in the extent to which individuals had a range of social contacts, unlike claims that all self-neglecters are anti-social and aloof … (2009, p 453)

and go on to highlight that hoarding behavior was completely absent among their sample, that – unlike in the classic studies of self-neglect in the elderly – the individuals concerned were in no way well-off, and that they also differed in that they mostly maintained close and ongoing – although often fraught – contact with health and social services. Commenting on what they see as the misunderstandings of this group, they suggest that:

> … it would be easy but over simplistic to consider these accounts as merely indicative of drug dependency and ineffectual parenting. Underlying these accounts is a sense that statutory services fail such clients, instead of supporting, inspire fear and mistrust. When a crisis occurs statutory services may respond punitively, as the above comments demonstrate this frequently exacerbates the initial presenting problem. (2009, p 452)

On the basis of their findings, they suggest a broader conceptualisation of self-neglect 'as a constellation of practical problems which health and social care workers encounter when working with this client group' (2009, p 448).

Finally, Olson et al (2007) conducted geriatric assessments and engaged in 'spontaneous conversation' with 20 people who were self-neglecting, matched with 21 controls. They were able to have open discussions about people's personal histories. Of those self-neglecting, 80 per cent exhibited at least two of the defining criteria. Their homes tended to be cluttered and dirty, compared to controls. Similarly, their appearance and personal hygiene were poorly attended to. Those self-neglecting tended to be much more revelatory in free-flowing conversation, spontaneously volunteering life course events. As such, they appeared much more eager to tell their stories. These included stories of being orphaned, of childhood physical and sexual abuse, of incest, and traumatic wartime experiences. At least one person had a lifelong struggle with sexual orientation. Some suffered from mental illness, while others were caregivers to loved ones with severe mental illness. One survived a murder attempt by a mentally ill spouse. Several told of struggles with alcoholism. Seventy-five per cent of those who were self-neglecting revealed one or more of these experiences, while fewer than 25 per cent of controls spoke of such experiences. The researchers concluded that these traumatic histories and life-changing events appeared to be associated with, and could possibly lie on the causal pathway to development of, frank self-neglect, which now included inattention to personal hygiene and/or environment, repeated refusal of services and self-endangerment through unsafe behaviours.

Taking this group of papers as a whole, one is forced to recognise the diversity of experiences that contribute to the cases of self-neglect described. While physical and/or mental illness may play a part, these researchers illustrate the importance of looking further and teasing out the possible significance of personal values, past traumas and social networks. In addition, a theme that regularly occurs in this body of work is that of the tensions that all too easily develop between health or social care workers on the one hand, and the self-neglecting person on the other. It is to be hoped that greater attention to the perspectives of people who self-neglect during the course of assessment and interventions with them, after the manner of these writers, can help to minimise this.

2.9   Variables as factors and correlations in self-neglect

Much of the work done over the past decade has consisted of studies that seek to establish which independent variables may give rise to self-neglect. In total, 52 studies in this review sought to measure the degree of correlation to be found between a given factor and a diagnosis of self-neglect. These papers typically use secondary analysis of casework data gathered from adult protection services or medical services for this purpose, in this way seeking to advance in incremental steps towards a more comprehensive model that can encompass all of these factors.

The range of variables that are considered in these studies illustrates how many contributory factors may play a part in cases of self-neglect. Among them can be found depression (Abrams et al, 2002; Burnett et al, 2006, 2007b, 2007c), diminished

social networks (Choi and Mayer, 2000; Abrams et al, 2002; Burnett et al, 2007a; Spensley, 2008), poor physical health (Choi and Mayer, 2000; Halliday et al, 2000; Tierney et al, 2004; Poythress et al, 2007; Dong et al, 2010a), poor mental health (Choi and Mayer, 2000; Halliday et al, 2000; Dong et al, 2010b), impaired physical functioning (Dong et al, 2007b, 2009b, 2010a), the economic resources available to the individual (Halliday et al, 2000; Abrams et al, 2002; Choi et al, 2009), lack of access to social or health services (Choi et al, 2009), impaired cognitive functioning (Choi and Mayer, 2000; Abrams et al, 2002; Poythress et al, 2007; Choi et al, 2009; Burnett et al, 2009b), functional impairment (Pickens et al, 2006a, 2007b; Naik et al, 2007a, 2008a; Poythress et al, 2007), pain (Pickens et al, 2007a), nutritional and vitamin deficiency (Smith et al, 2006; Aung et al, 2007; Burnett et al, 2008b), alcohol and/or substance use and misuse (Leibbrandt, 2008; Choi and Mayer, 2000), tocopherol levels (Aung et al, 2009), homocysteine (Burnett et al, 2009b), frontal lobe dysfunction (Al-Adwani and Nabi, 2001; Esposito, 2006), oxidative stress (Aung et al, 2008), personality traits (Dong et al, 2008a), traumatic histories and life-changing events (Olson et al, 2007) and high perceived self-efficacy scores (Naik et al, 2006). As is immediately obvious, many of these categories overlap and interact in both straightforward and more complex ways: for example, impaired cognitive functioning is likely to lead to functional impairment even though it is not the only factor that can cause it; impaired physical functioning may cause social networks to diminish as the individual becomes less mobile and less able to keep up social activities; depression may result from any number of the other factors listed here, and in turn may reinforce many of them as the depressed person loses the will to act to improve their situation. This reinforces the conclusion that self-neglect is often a complex phenomenon, which can stem from many causes (and it should be noted that those listed here do not include associations that emerged from qualitative interviews forming part of studies in the literature, and which may also play a significant part in self-neglect). The complexity is well illustrated by a study (Burnett et al, 2008a) that found no correlation between the independent variable studied and self-neglect. The research investigated whether elderly self-neglect was correlated with the APO e4 allele (a genetic marker for dementia) and showed no significant association between them; this is somewhat paradoxical, as dementia manifests through many of the factors shown to be related to self-neglect, but makes sense as an indication that dementia is only one of many vulnerabilities that may lead to self-neglect.

Relatively few of these papers make much progress in integrating the correlations identified into an overarching model that accounts for the causality of self-neglect. For instance, Abrams et al (2002) found that clinically significant depressive symptoms and cognitive impairment predicted self-neglect. Burnett et al (2007b) also found higher rates of depression and untreated medical conditions in cases of self-neglect. Dong et al (2010b), however, did not find a statistically significant association between elder self-neglect and depression or poor mental health, a finding echoed by Spensley (2008) in her review of recidivism in self-neglect cases. Unlike others who have found a correlation with reduced social networks and social resources (Choi and Mayer, 2000; Burnett et al, 2007a), they also found no significant association between self-neglect and levels of social networks. Similarly, Spensley (2008) did not find a significant relationship between self-neglect and social isolation. Choi and Mayer (2000) and Spensley (2008) in their samples also found a high

incidence of alcohol and other substance misuse problems, while Leibbrandt (2008) concluded that substance misuse was implicated as a risk factor.

One explanation for such divergent findings may reside in whether data reaches statistical levels of significance. Another may lie in the nature of the samples being studied. For instance, Tierney et al (2004) refer to risk factors and include here poor mental state, fewer social supports and resources and evidence of physical ill health. Halliday et al (2000) found that mental illness appeared to play a significant role in cases of squalor but not necessarily the severity of squalor, as did alcohol misuse, but depression and executive dysfunction were less common. Aung et al (2007) found an association between elder self-neglect and vitamin D deficiency, but the exact relationship remained unclear in terms of whether the deficiency was triggered or aggravated by the self-neglect. Burnett et al (2008b) found that low levels of vitamin D were associated with poor functional status while Smith et al (2006) found that individuals who self-neglect were at risk of altered nutritional status, including vitamin D.

Halliday et al (2000) found an association with physical disorders and decline, as did Dong et al (2010b). Pickens et al (2007b) and Naik et al (2007a, 2008a) found that self-neglect was correlated with impairments in basic and instrumental activities of daily living, or functional impairment. However, in their review, Poythress et al (2007) found only inconsistent evidence for associations with health and functional status, and also with cognition and mental health.

In such a potentially confusing picture, a multidimensional and multidisciplinary approach to assessment of medical, psychological and social needs appears indicated.

2.10   Models of self-neglect

Paveza et al (2008) concluded that there was a need for an overarching theory or common definition of self-neglect. Some authors have taken up this challenge. Abrams et al (2002, p 8) have suggested that 'self-neglect is a multifaceted entity involving a refusal to attend to one's own health, hygiene, nutrition or social needs'. This is assumed to result from mental, physical and social disturbances and also to promote such disturbances. A stepwise selection of risk factors included depressive symptoms and cognitive impairment as well as male gender, older age, low income, living alone and a history of physical disabilities. In a large-scale study, Dyer et al (2007b) saw self-neglect as related to multiple deficits in social, functional and physical domains. These, they suggested, lead to executive dysfunction which results in an inability to perform activities of daily living in a context that may well involve lack of access to, or refusal of much needed, social and medical services. When this is accompanied by a lack of capacity to recognise potentially unsafe living conditions, self-neglect results. The assessment of executive function and dysfunction therefore becomes important. Thus, they have proposed 'a model of self-neglect wherein executive dyscontrol leads to functional impairment in the setting of inadequate medical and social support' (2007, p 1671).

Gibbons has provided a theory of self-neglect that covers changes requiring new coping skills. The changes include physical, social, personal and cognitive change.

Gibbons also explored philosophy of life and death (personal control, protecting self, fears), cultural influences, social influences and family influences, concluding that 'self-neglect theory consists of two main concepts, self-care agency and deliberate action' (Gibbons, 2009, p 195). Cognitive impairment, mental health issues, coping difficulties, substance misuse problems, functional impairment, lifestyle/choice and personality may all lead to self-neglect where self-care agency (the power and capacity for self-care) and deliberate action (intent for self-care, a personal perspective on norms, standards, beliefs, values and motivations) are fluid and dynamic. Assessment then should focus on self-neglect due to deliberate action and/or low self-care agency. So, self-neglect here is seen 'not as much related to aging as it is to complex health and social circumstances and to an individual's ability and willingness to address these' (Gibbons, 2009, p 199). There are resonances here with Lauder and Orem's work (2001), which implicitly at least critiques medical models and discusses the degree to which definitions of self-neglect reflect an interplay between culture, context and the individual. For Lauder and Orem, self-neglect is as much a value judgement as an objective phenomenon. They too see self-care theory as able to explain some features of self-neglect.

Iris et al (2010) also offer a conceptual model that foregrounds personal, environmental and social risk factors as well as self-care deficits. As described above, their model includes the following features in order of importance: physical living (inability to care for self) conditions, mental health, financial issues, personal living conditions (lifestyle choice), physical health, social network and personal endangerment. Thus, physical and medical problems, such as chronic degenerative physical and cognitive diseases, may play a part, for example, Alzheimer's. So too might social factors make it difficult to meet personal needs, such as older people outliving their support systems, inadequate transport networks to make services accessible and poverty. Financial struggles, social isolation and cognitive deficits may predispose older adults to self-neglect. They may 'contribute to deterioration of personal living conditions and health, due to an inability to meet basic needs for health care, social support and self-care' (Iris et al, 2010, p 11).

The Iris et al (2010) paper is interesting because it contrasts socio-cultural with psycho-medical approaches towards understanding and intervening in cases of self-neglect. From the former emerges a conflict between an individual's choice, autonomy and self-determination, which might possibly represent an active or intentional form of self-neglect and local customs and community standards for what is believed to represent appropriate living. Self-neglect is a socially constructed concept emerging from perceptions and beliefs. In the latter approach, the emphasis is on associations with depression, cognitive impairment and other risk factors, deficits and disorders. Here the individual is seen as more passive. It is therefore interesting to consider if the uncertainty (see below) about whether to include self-neglect within adult safeguarding frameworks is associated with shifts between underpinning conceptual models, or even a swing between medical and social paradigms.

2.11   Workshop discussions on defining self-neglect

In the workshops participants thought it was difficult to determine what should count as self-neglect. The debate encompassed both the difficulty of differentiating self-neglect from other behaviours, such as people who might be refusing treatment when facing terminal illness, and the difficulty of determining when self-neglectful behaviour might reach the definitional threshold. As one workshop participant expressed it:

> 'Every single situation will be different. It's this whole thing, we are talking about thin lines, the boundary between what is self-neglect and what is eccentricity.'

Even if self-neglect could be defined and identified, there was uncertainty about whether it should be considered as a trigger for safeguarding. In particular, participants questioned why, if self-neglect came into the safeguarding frame (as acts of omission), self-harm should not also be included (as acts of commission). They both can have the same outcome and to include one but not the other was thought potentially to represent perverse logic. However, there were thought to be limits to what could be categorised as open to safeguarding interventions without posing challenges to and potentially compromising human rights.

Workshop participants expressed an interest in, and need for access to, research on self-neglect, and any guidance it might inform, in order to support practitioners and managers in their roles and to navigate through tricky dilemmas of identification and intervention. In particular it was felt that concept maps and models of self-neglect could inform what practitioners included in their assessment of self-neglect cases.

3 Questions of capacity

While capacity is to some extent implicated in all references dealing with self-neglect, as it ultimately is the major determinant of the distinction between Gibbons et al's intentional and non-intentional self-neglect (2006), or Dyer's inability or unwillingness to self-care (Dyer et al, 2006a), some papers bring it out in more detail than others. Of those included in this review, 48 references singled capacity out for significant attention in one way or another. These ranged from case study reports of a psychiatric nature, which as a matter of course described the assessment of capacity in the patient (Al-Adwani and Nabi, 2001; Harris et al, 2009), to those which make the ethical and practical debates around evaluating capacity in self-neglect their central theme (Lowe et al, 2000; Preston-Shoot, 2001; Black and Osman, 2005; Naik et al, 2008c), with most devoting some intermediate level of attention to the issue of capacity, among other themes.

3.1 Capacity in the literature

Capacity to make decisions should be distinguished from the more global attribute of cognitive functioning, in that capacity is function-specific; it applies to the ability to decide on a specific question. Someone can therefore have capacity on some decisions but not on others. Naik et al define a person's capacity as the ability:

> ... to make a decision themselves or to pass that decision on to another person if impaired (decisional capacity); and the process of putting that decision into effect alone or by delegating to another person (executive capacity). (2008b, p 9)

This formulation, which underpinned the researchers' development of a screening instrument, focuses therefore not only on the ability to weigh up information in order to come to a decision but also on the ability to implement and adapt plans. It is echoed by Dyer et al (2007c), who distil the essence of capacity into the ability to plan and carry out tasks. Cooney et al (2004) consider that executive function is superior to global cognitive function as a measure of decision-making capacity. They define this as:

> ... an integrated set of cognitive abilities, including flexibility, concept formation and self-monitoring. Patients with impaired executive function need not have impairment of memory or basic cognitive processes. [The] condition does, however, have a major impact on volition, judgement and planning.[...] The ability to carry out and implement personal choices requires intact executive control function of the brain. This function allows an individual to integrate simple tasks into goal-directed behaviour. These functions are essential for planning goal-directed tasks and for adjusting to changes in the environment. (Cooney et al, 2004, p 359)

Thus capacity must entail both the ability to make a decision in full awareness of its consequences, and also the capacity to carry it out. Torke and Sachs (2008), commenting on the paper by Pavlou and Lachs (2008), further specify that an individual may have intact cognitive functioning when tested but may still not have

capacity if they cannot see the consequences of their decisions. In other words, cognitive functioning and capacity are separate, with the latter determined against specific decisions. Taken together, these two papers concluded that cases may be handled differently when what is presented appears to be part of a lifelong pattern of behaviour as opposed to a recent change. Behaviour that is consistent with previous life choices should, the researchers argue, be regarded as authentic and a reflection of that individual. Changes in behaviour, however, may be indicative of new diagnoses, for example, depression. Following this argument, a failure to provide for one's own needs may not necessarily be attributable to lacking capacity.

According to Naik et al (2008c), there are two main ethical approaches that may apply to judgements of capacity. The first, which is usually given priority, is deontological, and refers to the application of a guiding principle for its own value, in this case, the right to autonomy in decision making. The second is consequentialist, and guides judgements on the basis of the likely consequences that may ensue; here a person might be ruled not to have capacity and their choices overridden if to do otherwise was likely to bring about consequences such as a serious deterioration in their health. Naik et al argue that under both philosophical rules, there are grounds to deny someone's autonomy where they are lacking in either decisional or executive capacity:

> From a deontological and consequentialist perspective, the individual's autonomy, health, and safety are all at risk if either dimension (decisional or executive) is impaired. (2008c, p S267)

This distinction between decisional and executive capacity leads some authors (for example, Sherman, 2008) to advise that assessment should follow an 'articulate–demonstrate' model, encouraging the person who is self-neglecting both to outline their approach to decision making, and to reflect and illustrate how they will put their resolutions into effect.

The significance of capacity is readily apparent to most interested observers; Dakin and Pearlmutter's study (2009), which employed focus group methodology to investigate the general public's views on self-neglect, showed that participants implicitly took capacity into account in reaching their judgements. Iris et al (2010) suggest that it is likely to be a central factor in determining the care pathways of younger people in particular. They argue that elder self-neglect differs from that in younger adults due to its association with cognitive impairment and/or age-associated diseases that restrict or limit self-care, for instance, heart failure or arthritis. However, the only study to have carried out systematic research on professionals' employment of capacity concepts is that by Lauder et al (2006). They used vignettes to test nurses' decisions on capacity in self-neglect situations. Their results showed that whether or not patients were diagnosed with a mental illness accounted for 88 per cent of variance in their answers, and that the conditions of squalor described in the vignettes had barely any influence. Ability to perform activities of daily living, specifically feeding and toileting, also exerted influence on the nurses' perceptions of capacity, reflecting perhaps how they viewed what Naik et al call 'executive capacity'. Iris et al's observations on younger people also found echo in Lauder et al's research, as the nurses were more likely to use statutory intervention

with younger people. Lauder and his co-authors point out that although mental illness and capacity overlap, they are not one and the same thing, suggesting that this is an area that might be explored in further work on how professionals approach capacity. While the use of vignettes in this way allows for the careful control of experimental variables, one might question the extent to which the manner of presentation ends up influencing the nature of responses; however, the present review located little published research specifically into how professionals currently work with issues of capacity in self-neglect, and so this study may be of interest in an under-explored area.

On a side note, in light of the suggestion that younger people who come to the attention of safeguarding services for self-neglect are more likely to be diagnosed with a mental illness than older adults (Halliday et al, 2000), the following quotation from another study by Lauder et al, which focused primarily on a younger population, is interesting:

> Where there was no psychiatric diagnosis, the rationale for intervention was much less comprehensive. Self-neglect was often considered a lifestyle choice and professionals did view self-neglect as being a problem of the client's making, rather than attributing this to also involve environmental or social causal factors. Without a medical diagnosis, clients were not offered specialist psychiatric health care and their access to social work or other support was also extremely limited. They were more likely to be the subject of enforcing intervention through environmental health or housing services. (2005c, p 322)

There are a number of conditions that can affect capacity to weigh up choices and to understand their potential consequences, and so a number of authors call for screening for conditions (depression, dementia, executive dysfunction) that could affect capacity to take place as early as possible (Dyer and Goins, 2000; O'Brien et al, 2000, p 12; Sengstock et al, 2000; Reyes-Ortiz, 2001; Tierney et al, 2004; Lebert, 2005; Pavlou and Lachs, 2006a; Dyer et al, 2007b; Ballard, 2010, p 183), as the outcome will affect all future decision making with regard to the client. It is important to note that capacity is not automatically negated by mental disorder, which may well leave it intact in some areas and at some times (Ballard, 2010, p 183), although this also implies that capacity may at times be transitory, with the potential to fade away as well as to recover (Sengstock et al, 2000). Even where capacity is lacking, the professional is still ethically obliged to apply the least restrictive measures when intervening, in accordance with what is known of the prior values of the individual concerned (Bergeron, 2006, p 92).

Capacity can often be a cause of frustration for adult protection services workers, as clients can refuse care or opt for non-adherence to medical recommendations (Valios, 2000; Harbison et al, 2004; Dyer et al, 2006a, p 7). Hence, if someone who is self-neglecting is considered to have capacity, health and social care professionals are markedly limited in the extent to which they can intervene; indeed, intact capacity is sometimes seen as ruling the individual out of the realm of self-neglect. Hence 56 per cent of the adult protection services workers interviewed by Dyer et al (2006a) classified only those who were unable to take care of themselves as engaging in

self-neglect, excluding those who were unwilling, and Payne and Gainey (2005) cite a declaration from the (US) National Center on Elder Abuse which states that:

> The definition of self-neglect *excludes* a situation in which a mentally competent older person, who understands the consequences of his/her decisions, makes a conscious and voluntary decision to engage in acts that threaten his/her health or safety as a matter of personal choice. (p 24 emphasis added)

This view stems from the legal force given in many countries to the principle of individual autonomy. Indeed, the strong focus on autonomy derives from a well-established North American tradition (Dyer et al, 2007c). For professionals confronted with situations of possible self-neglect, however, a conflict of ethical values arises between this value and the principle of beneficence – the worker's duty to act for the client's wellbeing (Simmons and O'Brien, 2000; McDermott et al, 2009).

Not everyone is convinced that self-determination should always trump the real and serious risks which may present in severe self-neglect. Some references warn in passing of the dangers of ignoring significant health risks on the grounds that the person has been judged mentally competent (Simmons and O'Brien 2000; Arluke et al, 2002). O'Brien et al spell out the dilemma:

> This complexity [ie, that inherent in capacity] is compounded by the fact that respect for autonomy and personal rights are given paramount importance over paternalism when an intervention at an earlier stage could potentially result in a better outcome. (2000, p 16)

Bergeron (2006), in a nuanced and sophisticated discussion, explores the potential limits to the principle of self-determination. She argues that the principle of self-determination is affected by a number of considerations in cases of self-neglect. In contrast to the individualism commonly valued in the US, she lists a number of additional considerations that may mitigate the principle of self-determination, such as community rights not to be exposed to the squalor; risks, experiences or sights that may accompany self-neglect; the effects of learned helplessness or depression; the possibility that the client may resist being proactive in resolving the situation because they see it as the professionals' role rather than a mutual project; and the possibility that the client may be unable to envisage acceptable alternatives to their current circumstances. Preston-Shoot (2001) also explores alternative value systems to self-determination in the context of two cases of elder abuse and when intervention might be justifiable when adults do and do not have decision-making capacity. Black and Osman (2005) go as far as to suggest that people who self-neglect are often wrongly thought to have capacity when this is not in fact the case. They argue that a truly ethical approach must take account of other considerations, and that a preoccupation with self-determination risks obscuring the importance of the principle of beneficence (see also Preston-Shoot, 2001). Their own ethical emphasis falls on the value of doing least harm.

Against this there are the counter-arguments in favour of respect for self-determination. Having put the case in favour of beneficence, Simmons and O'Brien equally recognise that:

> Medical beneficence must not become a euphemism for depriving older persons of the last vestiges of personal autonomy, the remnants of the dignity by which and for which they have fashioned their lives. (2000, p 52)

Thibault et al (2000) also warn that all too often the complaints of people who neglect themselves are dismissed because they are seen as lacking capacity, and that they are thereby forced to accept undesired and unwelcome interventions. Lauder et al (2002a) similarly are at pains to emphasise that medical discourse all too often can disempower the individual by tending to cast doubt on their capacity.

Ultimately most of the authors on both sides of this argument recognise that the tension cannot be resolved by favouring one view or the other. Rather it is seen as vital that those charged with assessing and intervening in self-neglect adopt a position that takes the many different aspects of the situation into consideration. Black and Osman (2005), for example, are at pains to argue that assessment should ideally involve multiple professional perspectives, formal tools and interviewing techniques, as well as taking into account the social networks of the client, cultural expectations, personality characteristics and communication patterns, in order to find the balance between the two principles. Likewise, Heisler and Bolton (2007) state that comprehensive, interdisciplinary responses are required from early on in contact with the individual, to deal with the complexities of capacity. Lowe et al (2000), accepting that assessment for capacity when self-neglecting patients wish to remain at home is a complex task with no universally agreed measure, suggest that if the patient's capacity is adequate their decision must be accepted, but when it is not, they suggest that either the decision should be 'defused' by finding ways to change the complexity or consequences of the decision, or the patient's decision must be overridden in their best interests (2000, p 181). Hazelton et al (2003), dealing specifically with capacity considerations in cases of alcohol misuse, which may be implicated in some cases of self-neglect (Choi and Mayer, 2000; Leibbrandt, 2008), make a number of suggestions relating to the assessment of capacity, including taking care to distinguish between cognitive deficits and denial secondary to addiction, preferably waiting for the effects to wear off before assessing capacity, and advocating repeat testing at a later date if there is any suggestion of improvement. The thinking underlying such recommendations has application beyond the issue of substance misuse, particularly the attention to circumscribing carefully the specific effects of any given disorder on actual capacity, and to monitoring the possibility of changes in capacity on an ongoing basis.

In a thoughtful paper, Dong and Gorbien (2006) advise professionals dealing with such questions to give due consideration to decision-making capacity as a spectrum rather than a simple dichotomy, factors that may influence it, levels of risk consequent on the decision, the risk of harm to others (dependents or neighbours) and cultural issues that may affect capacity. In this regard, they advocate a number of strategies, largely concerned to build a relationship with the individual that allows their narratives to gradually unfold and inform decisions. First, they suggest that analysing the situation in practical terms may be more useful than attempting to make progress purely through the application of ethical principles; in other words, focusing primarily on solutions rather than first principles may often offer a useful way forwards. Second, they make the point that respect for the individual's

independence does not, and should not, mean disengaging from continued involvement with them:

> Honoring autonomy does not preclude further understanding of the values underlying an individual's decision-making or help clarify a patient's anxiety and awareness of what is at stake. Respect for autonomy does not denote that involved parties detach themselves from an elder's autonomous decision-making process. Understanding the patient's values, continued attempts to persuade the patient, and ongoing conversation with the patient, are also ethically valid choices. (Dong and Gorbien, 2006, p 29)

Ongoing commitment to the patient allows time:

> ... for stories to unfold, to examine options informed by those stories, to test possibilities, and to revisit problems, more than once if necessary. (p 30)

Third, they suggest that fully informed multidisciplinary collaboration can help promote genuinely independent choice while minimising exploitation (p 30). For this to occur, it is important that professionals be capable of 'self-examination of ethical values' (p 31) and 'learning from each other's views' (p 35). Finally, paying attention to the 'continuum of available interventions' (p 32) in order to identify the least restrictive options on offer should also be a priority for all team members. Where all these ingredients are present, it becomes possible to achieve the optimum balance between autonomy and beneficence.

A number of references point out in passing the need for professionals to consider capacity when assessing suspected self-neglect (Lauder et al, 2005a; Dick, 2006; Dyer et al, 2007c; Day and Leahy-Warren, 2008b; Pavlou and Lachs, 2008; Murray and Upshall, 2009), but a limited number make suggestions for how to do so effectively and more accurately. Schillerstrom et al (2009) identify that despite the relevance of executive function to decision-making capacity, executive measures are rarely used during capacity assessments. They present evidence that self-neglect may be associated with loss of executive function from their study which found that people who were known to adult protection services as a result of self-neglect had worse cognitive performance than those investigated as a result of abuse or exploitation, although those who were also living in squalor were no more impaired than those engaging in other forms of self-neglect.

Naik et al (2008b) call for use of the 'Articulate–Demonstrate' method by professionals, an approach which evaluates both decisional and executive aspects respectively. Sherman (2008) too recounts how such a method has been useful in his clinical practice to assess ability to manage finances; he asks the person to describe how they would go about paying their bills, and then asks them to write a specimen cheque for a specified amount in front of him. This approach goes some way to overcoming the difficulty that many people who self-neglect:

> ... retain communication and social skills and often make claims about their abilities that are inconsistent with actual performance ... (Naik et al, 2008c, p S267)

although it does not offer detailed guidelines for a fully comprehensive assessment of self-care capacity.

In order to assist with the identification of decision-making capacity, several papers develop and test self-neglect capacity screening scales (for instance, Dyer et al, 2007a; Naik et al, 2007b, 2007c, 2008c; Kelly et al, 2008). These are discussed in detail below in Section 5.2 on detection and intervention. Their importance lies in the recognition that, without such tools, professionals may be swayed in validating self-neglect by impressionistic judgements of impaired cognition (Dyer et al, 2007a, p 16).

Less prominent in the literature on self-neglect and capacity is a focus on the legal rules. This is reflective of the discourse focus within the literature where vulnerability was the dominant orientation (in 106 of the 155 papers), with only six papers approaching self-neglect from a rights perspective and another five taking an empowerment stance. Ballard (2010), having determined that a determination of capacity shapes how community nurses can intervene in self-neglect cases, then reviews the legal framework in Ireland. Dyer et al (2007c) noted the importance of assessing capacity prior to imposing legal interventions. Pavlou and Lachs (2008) have also recognised that an absence of capacity allows legal interventions while an assessment of decision-making capacity leaves practitioners having to rely on negotiation skills. Connolly (2008) provides a more critically reflective paper, arguing that types of legal intervention may serve to protect vulnerable older people but should not inappropriately infringe someone's civil liberties or result in exploitation. She recognises the difficulty in deciding when responsibility for care shifts from the autonomous individual to another person, in guarding against premature, unnecessary or inappropriate action and in avoiding the negative outcomes that legal interventions can sometimes precipitate. Naik et al (2008b), writing in a US context, have also cautioned against seeing capacity as an either/or threshold phenomenon, proposing instead that capacity be viewed as a clinical gradient in order to avoid unnecessary infringements of patients' rights. When impairments are severe and other interventions have failed to ameliorate them, legal steps might be necessary.

A number of papers (Bergeron, 2006; McDermott et al, 2009; Murray and Upshall, 2009) explicitly acknowledge the importance of practitioners being familiar with legal rules within their local jurisdiction, although by and large they do not offer further amplification or detailed recommendations. Others writing in the UK context (Gunstone, 2003; Lauder et al, 2005a) comment on workers' lack of confidence in working with legal frameworks and report particular lack of knowledge and confidence in respect of the Mental Capacity Act 2005 (Harbottle, 2007) and difficulty seeing how to use provisions in the Human Rights Act 1998, *No secrets* and the Data Protection Act 1998 (Perkins et al, 2007; Pinkney et al, 2008). In contrast, workshop participants in the present study were clearly engaged in active consideration of the role of legal rules.

3.2 Key informants' perspectives on capacity

Capacity was a central focus for key informants. They clearly differentiated between people who self-neglect and have capacity and people who self-neglect but are seen not to have capacity. The latter came within the scope of the Mental Capacity

Act 2005 and its *Code of practice* (DCA, 2007). For those seen to have capacity, reliance had to be placed on 'good social work'. However, one key informant felt that the Act could be better used and understood, and that the decision-specific nature of capacity could raise complications if not understood and assessed properly. An example was given of practitioners assuming that because a person who uses services had capacity to refuse entry to her house, her capacity extended to choosing to neglect her hygiene to the extent of not moving from her chair, yet failing to recognise that the pain of movement was arguably such that capacity to make and execute the decision to move was arguably impaired.

That said, for this key informant, on a spectrum of principles from "we must do everything we can to protect people, even if that means protecting them from themselves and overriding their wishes" at one end, to the other end, whether called 'personalisation choice and control' or whether called 'autonomy and self-determination', the orientation was much more towards the latter. This did not mean, however, that nothing was and could be done. It meant a detailed assessment of capacity and, where that was established for each decision, it meant that professionals had to rely on a different set of tools, such as relationship building, for intervention.

For another key informant implementing mental capacity legislation in practice was "a little bit fraught", with insufficient "case development of practice here yet to be helpful to people". This key informant cautioned against assuming that, once assessed as having capacity, an individual would always be assumed to have capacity. Implicit was a concern to ensure that capacity assessments were rigorous and covered "what would be in their best interests" too, "because best interest seems to come out of incapacity assessment as opposed to capacity assessment".

Risk management and best interests decision making were seen as requiring:

> '... very confident practitioners, very confident managers, who are prepared to take on board very complex risk management across agencies which may not be through a safeguarding pathway, but be very close to it and so they do need a kind of complex case conferencing arrangement in order to come to conclusions, and they do then need to revisit their capacity assessment, on a very regular basis because week one, the person may have capacity and the harm to themselves and others is emerging but it's not life critical. Week four may be a totally different assessment and whichever professional is still getting through the door may have the chance to persuade and engage and confront those issues.' (Key informant)

This was very challenging work,

> '... because no practitioner wants to feel that they should or could have done something more (and therefore) the strength of support of a multi-agency decision-making tool, if it's not got close to safeguarding, is absolutely vital to those considerations.' (Key informant)

Moreover, this key informant could conceive of a situation where severe self-neglect that was life critical could be in itself evidence of incapacity.

3.3   Workshop and focus group discussions on capacity

In terms of intervening in cases of self-neglect, capacity was seen as central. As with the literature review, the complexity or nuances of the interlinking components that comprise decision making and executive capacity was captured in discussion. In particular, there was a concern that decision-making capacity should include, but often did not, assessment of a person's ability to implement a decision. For example,

> '... there's a difference between capacity, understanding, being able to process the issues and actually being able to do something about it and have the resources, in the widest sense, to change the situation and that includes other people that might have capacity but are not being allowed to exercise it.... It might be borderline capacity because it's a spectrum isn't it but certainly not the skills, the resources, the notion of strength to actually deal with something and I think that's the real difficulty for us....' (Focus group participant)

A workshop participant also captured the nuanced and multilayered nature of capacity:

> 'We've developed ... a hoarders/self-neglect policy and we're just in the process of piloting that with 20 of our top hoarders/self-neglecters, with all agencies coming together. I suspect some of those people have capacity, I suspect some of them don't have capacity, and it sounds awful but what we also have to hang on to is, it's capacity to do what, isn't it, not capacity right across the board, so you can actually miss some of the nuances of that.'

There was general agreement that it was vital to understand the meaning and significance in the individual's situation and context. While potentially life critical, self-neglectful behaviour could be an attempt to escape from a particular environment or situation. Cases were described where action had eventually been taken, in respect of adults without capacity for instance, and where the individual had expressed relief and/or appreciation once they had been removed from their difficult situation.

The complexity and nuanced nature of capacity emerged, for example, when discussing hoarding. Some people go through life collecting things and psychologically it may be quite adaptive as behaviour at various points in a person's life, but then at another point that very same behaviour may become maladaptive. The literature offers assessment tools but these may not be used in much social work and healthcare practice, which raises questions about the degree of sophistication in assessments of capacity. Do they, for instance, explore a person's historical way of relating to the world and therefore pick up how that historical way of relating to the world may now have actually become a redundant solution because of the different position in which they find themselves, physically as well as mentally? The impact of the past was also referred to by a focus group participant who questioned whether

some individuals could understand particular choices they were making on the basis of life experience punctuated by a series of sexually abusive relationships.

The complexity of assessing capacity can be illustrated by the challenge of accounting for the cumulative impact of a series of small decisions, each taken with capacity but together amounting to a situation that is not 'chosen'. Capacity is decision-specific and self-neglect or the kind of end picture of self-neglect that is seen in practice may be the result not necessarily of a specific choice to live that way but about the exercise of individual small decisions about small things, like 'shall I eat today?' or 'shall I go to the toilet?' or 'shall I wash myself today?'. So those small decisions that the individual has capacity to make on a moment-by-moment, day-by-day basis potentially add up to an end result that has not been consciously chosen but which has developed through a spiral of cumulative impact. Once again, staff may not have the training and skills to investigate such a picture:

> 'It's that whole thing about understanding the consequences of your collective decisions as well as the long-term impact, and when people very often do those assessments now it's based on the single incident or the single decision at that specific point in time and that's why, even if you're supporting somebody to make risky decisions, you need to keep reviewing, you can't just say that person is self-neglecting, there is no more I can do and walk away. You have to keep revisiting to see if there is anything you can do to change that behaviour or just to make sure that it doesn't become more and more risky and more and more dangerous. But I think that we don't do it well because we actually look at the now. It's always been one of my things when people are discharged from hospital and social workers do an assessment for the discharge, they're actually doing an assessment in crisis or just post a crisis, actually an assessment needs to think about the future, not what's happening right now but the longer term and we don't do that. I don't think people are actually trained to do that or skilled enough to do it.' (Workshop participant)

Some concern was expressed, then, about whether capacity assessments were being carried out as thoroughly as needed, in part perhaps due to this being a relatively new knowledge and skills area for staff. It was thought essential to have confidence in the capacity assessments undertaken (and there was consensus that the Mental Capacity Act 2005 may not be well understood, for instance in respect of young people in the midst of transition between children's and adult services). These should include assessment of the person's understanding of the overall cumulative impact of a series of small decisions, for which they do have capacity, but where they do not have capacity to understand the overall impact. Distinctions between active and passive harm, and harm by own or others' actions, were thought perhaps to be false ones, although it may be the case that someone who does not actively choose to self-neglect but cannot prevent it may be more amenable to intervention; the question then was one of how far choice was being exercised, with capacity to do so with full understanding of the consequences.

It was also considered that capacity assessment should be revisited iteratively to account for fluctuation and variation, with recognition of the time and skill that it may take to build the kind of relationship in which such judgements can be made

and individual history can be understood – a service sounding rather like care management, or even what a number of participants called "good old fashioned social work". Relationships, time, manageable workloads, skilled assessments, supervision and adequate training would all be significant, as serious case reviews in respect of children have identified routinely.

A legal literacy around the Mental Capacity Act 2005 emerged, then, as important. Some participants expressed concern at whether the complexity of the legal rules, both the Act and subsequent guidance, surrounding the assessment of decision-making capacity had been fully understood by those responsible for making such judgements. For example, in the following quotation there is a sense of unease as to whether assessors have fully grasped the complexities. At the same time, the focus group participant is highlighting again the importance of decision-making capacity assessments that include coverage of a person's ability to implement the decision they wish to take, to convey how they propose to address their situation – what the literature sometimes refers to as executive capacity.

> 'People have got to remember it's decision-specific and a person on face value may have mental capacity but when you take time to explore and formulate your question around self- neglect, to me, we need to be using questions that are very, very clear, maybe based on the risk assessment … "do you understand the implications of living in … you might get … you know, possibility of rats, mice, people breaking in and you wouldn't know". Because to me it's too easy to walk away from situations by saying well they've got capacity but I would find very few people would be happy to live in those circumstances really without taking on board that there probably is some deficit somewhere and I think that was a good example. They may have capacity to actually understand and process that information but they haven't got the wherewithal to actually deal with the situation and rectify it in anyway.' (Focus group participant)

A sense was conveyed that this kind of assessment required an experienced practitioner but that such expertise was not easily gained. Thus:

> 'I think you need a good understanding of risk assessment and I think you need relatively experienced people to be able to do that assessment and I think the only way to get experience is to do the job, so it's not a perfect system at all.' (Focus group participant)

Equally, repeat assessments might be required as well as ensuring that curiosity and appropriate challenge is embedded within an assessment. Some participants were concerned that assessors could accept the first, and potentially superficial, response rather than interrogating more deeply into how a person understood and could act on their situation. For example,

> 'It is about going back and just checking capacity without changing the threshold of capacity but just investigate, making sure you have checked properly. Because again I mean often lots of examples of someone saying "oh they've got capacity to make their own decisions" but … superficially

somebody that can say yes and no but not in terms of really understanding the implications.' (Focus group participant)

Moreover, within that determination of capacity, a proper process had to be followed, preferably involving more than one visit, a focus on assessment of risk as well as capacity and a multi-agency approach. One case was described where a family had complained because this had not happened:

'I think the family were unhappy with how we'd acted, quite rightly I think, and I think if there had been clearer risk assessment processes in place, better recording issues around capacity, obviously it's specific to specific decision making, then I think we would have got a different result for that person and I think that there is something there about being clear and involving ... not just actually making assumptions about situations but actually having clearer intent and actually being very clear in terms of what you're looking at and how you ought to record it, and what you're deploying in terms of risk assessment, which is not so easy I guess when it's just another person being discharged from hospital.' (Focus group participant)

So, the assessment of capacity meant not just an initial judgement and/or acceptance of superficial presentation. It had to be decision-specific rather than a blanket assessment, with periodic reassessments. It had to be challenging in the sense of exploring the degree to which an individual understood the long-term consequences of their behaviour. It was an approach rooted in concern that agencies might not want to accept responsibility or, even where they do, might not be resourced sufficiently to implement good practice:

'I get social workers coming to me and saying, there is nothing I can do, they almost abandon the people right at the beginning because they almost want to see at the end, there is nothing I can do anyway because they have capacity. You've got to try and do something, you can't just say well this history is that last year the environmental health officers went around there and cleaned it all up and now we're in the same situation again and what we are going do as social care, you're going to say she's just going to do it again, do you really know why she's doing it, is it because ... no good writing a letter because she might not be able to read. Looking at really, really unpicking that and I don't think we have the capacity to do that, to really get down to work with people on a long-term basis on why they are doing that and do we need to look at other ways of the system helping.' (Workshop participant)

Overall, then, workshop participants concluded that assessment of capacity needed to be more rigorous in determining decision-specific questions, an end point which may also be drawn from this review of the published literature. While some participants believed that more robust tools for assessment of capacity were now available, others were concerned at the lack of legal and practice literacy surrounding the Mental Capacity Act 2005, which could lead to superficial decisions that individuals had capacity and/or that nothing could be done, or that the number of domains to be covered in an assessment acted to deter people, with a consequent assumption that capacity was too difficult to assess. It was questioned whether self-

determination should/could be promoted when a situation is life critical, and there were probably diverse views on where one might draw the line. It was not uncommon for self-neglect cases to become the subject of serious case reviews. In terms of what emerges as learning, one point was the need for good practice guidance in recording to ensure that reasons for decisions are logged rather than just the decisions themselves, particularly where no intervention is made and/or a case is closed. This was a question of being clear about what in the situation absolves professionals from a duty of care. It was also thought important to explore how to transfer learning from existing multi-agency systems where 'resistance' may characterise the relationship between user and professional, for instance CPA, multi-agency public protection arrangements (MAPPAs) and multi-agency risk assessment conferences (MARACs).

4 Self-neglect and inclusion in safeguarding

4.1 Perspectives on self-neglect and safeguarding from the literature

Legal and procedural frameworks applied to the safeguarding of people who self-neglect vary not only from country to country, but even within countries. Where self-neglect most clearly and consistently falls within the purview of safeguarding, in the US, individual states may differ in how their adult protection services tackle the problem. Fulmer describes how, while most states had introduced mandatory reporting laws of some sort for elder mistreatment by the mid-1980s, they assigned responsibility for dealing with identified cases in different ways, and argues that, even in the present day:

> ... in practice, there remains great variability in strategies for detecting, assessing, and reporting elder mistreatment and, in particular, elder neglect. (Fulmer, 2008, p S241)

This view is seconded by a number of other authors, leading O'Brien et al to comment that:

> ... with regard to reporting elder abuse, elder-neglect, and elder self-neglect, there is no federal policy, but rather, "50 variations on a theme". (Thobaben and Anderson, 1985, cited in O'Brien et al, 2000, p 12)

The range of variety of forms that state definitions take has already been highlighted; it now becomes clear that this also affects how self-neglect is acted on once identified.

For example, Abrams et al (2002) mention that in Connecticut, referrals to the Elderly Protective Services Agency may be made by mandatory reporters, such as healthcare workers having direct contact with clients, or by non-mandatory reporters, such as relatives, neighbours, postal workers, clergy or other citizens who come into contact with possible cases of self-neglect or abuse (2002, p 1725). In Texas, however, reporting obligations go further than this, as *all* citizens are mandatory reporters (Dyer et al, 2006a, p 3; Aung et al, 2007, p 3; Franzini and Dyer, 2008, p 668); Simmons and O'Brien mention that this is also the case in Kentucky (2000, p 43). There is considerable variation throughout the country, as evidenced by Lauder et al's comment that registered nurses are mandatory reporters of self-neglect in around 60 per cent of US states (2006, p 280). In the time period under review (2000–10), no studies were identified which specifically addressed the extent to which this made a difference in reporting rates or public awareness of self-neglect specifically, although this would be an interesting topic for study. It is possible that this might be one of the factors behind the differing intervention pathways in operation, alongside the distribution of resources and the historical development of adult protection work in the different jurisdictions; in Connecticut, the assessment following a referral is initially undertaken by the state ombudsman on ageing, before going to Elderly Protective Services Agency if further action is shown to be needed (Abrams et al, 2002, p 1725). In Texas, on the other hand, the referral is directly to adult protection

workers in the Department of Family and Protective Service. For all this variation, however, what is relatively consistent is that self-neglect (at least in relation to older people) is a problem accorded high visibility and for which there are usually reasonably clear procedures to follow. This has led Lauder et al to voice the opinion that, although not perfect,

> ... the state-based APS system in the USA has no real equivalents in other countries and may be the most comprehensive, enlightened and proactive system to be found. (2009, p 448)

Making specific reference to the UK, they add that:

> ... the recent Protection of Vulnerable Adults legislation has been implemented, but it is noticeable how little self-neglect features in this initiative. (2009, p 448)

Other authors agree that the firm guidelines informing action on self-neglect in the US are not seen to have an equivalent in other countries. Gunstone (2003) portrayed the framework informing action on self-neglect as a 'grey area' within community mental health work in the UK, noting that while mental health workers made use of CPA and the Mental Health Act 1983, they were less likely to employ the Mental Health (Patients in the Community) Act 1995,[3] or local procedures on the prevention of abuse of vulnerable adults. Although the practicalities of dealing with self-neglect in the US are fraught with their own uncertainties, there appears to be more guidance available there on how best to deal with the framework within which assessment takes place. Like Gunstone, Lauder et al (2005c) also found considerable variability in how UK services responded to self-neglect, noting that a client who had a psychiatric diagnosis was likely to receive a much more thorough intervention, and suggesting that broader, multidisciplinary structures (for example, incorporating housing and public health officers) are required than those usually in place. Meanwhile McDermott (2008, p 233) notes that in Australia too self-neglect is not legislated for specifically. Likewise in Ireland,

> ... no specified reporting procedure or legislation exists to guide the health care provider in relation to self-neglect cases.[...] As the legal requirements for reporting concerns of self-neglect are not clear in Ireland, the discretion used by the nurse making home visits is paramount. (Ballard, 2010, p 184)

Of course, Lauder et al's (2009) praise for the system in the US is counterbalanced by a number of critiques from other quarters. McDermott notes that the reasons why the US example was not followed in Australia lay in the belief that specific policies around elder self-neglect encourage ageism, that mandatory reporting is no more effective than voluntary reporting and that mandating responses to self-neglect does not ensure that funding will thereby become available to permit an adequate service (2008, p 233). As a result, it was decided not to create specific legislation and service pathways for self-neglect, but rather to deal with it within existing services.

Simmons and O'Brien are concerned with the possibility that mandatory reporting rules, such as those in operation in the US, can at times have negative effects. They draw attention to the conflict between the health professional's duty as the

patient's primary advocate, with an ethical obligation to respect their autonomy and confidentiality, and the state's insistence that the professional over-rule these standards by reporting the case to adult protection (2000, p 43). While this ethical tension is inherent in a range of healthcare encounters, it becomes particularly salient in self-neglect, where individuals frequently present with an existing mistrust or refusal of services (see, for example, Kutame, 2007) which may only be worsened by actions that may be seen as a betrayal of confidence, and where there may be no third party abuser.

Dakin and Pearlmutter supply a useful summary of some of these issues, pointing out that the issue of mandatory reporting is still controversial in the US, despite having been adopted in 'more than four fifths of states' (2009, p 16). They continue, laying out the case against:

> Those opposed to mandatory reporting (favoring autonomy) statutes voice the concern that they are paternalistic and limit self-determination, engender helplessness by discouraging victims from reporting abuse on their own behalf, and lead to stigmatizing and intrusive investigations with resulting losses in privacy and confidentiality[...]. Furthermore, because of limitations in service availability, mandatory reporting may lead to solutions (eg, nursing home placement) that are worse than the abuse[...]. Additionally, research indicates that public and professional awareness of elder maltreatment are more important than mandatory reporting laws for case identification[...]. Other research has found that mandatory reporting statutes are not associated with higher rates of reporting, although they are associated with higher investigation rates[...]. (Dakin and Pearlmutter, 2009, p 16)

On the other side of the argument,

> Those in favor of mandatory reporting statutes (favoring protection) believe that they lead to the provision of essential services for people, most of whom request or consent to these services[...], and have the potential to improve quality of life[...]. Others have argued that passage of mandatory reporting laws allows reporters to feel protected and more comfortable in making reports[...]. (Dakin and Pearlmutter, 2009, p 16)

They reach no final conclusion on which position is the correct one, but their summary of the two sides of the argument raises points that should be taken into consideration in any system.

Finally, it is worth considering whether it is appropriate for self-neglect to be included within safeguarding as a sub-category of mistreatment. For example, Payne and Gainey suggest, on the basis of their study findings, that self-neglect cases – despite certain similarities to elder abuse cases – generally have 'fewer vulnerabilities than other elder abuse victims' (2005, p 33). While people who self-neglect commonly suffer from alcohol problems and psychiatric problems, Payne and Gainey go on to wonder whether part of the explanation as to why they often tend to refuse protective services is that 'they simply may not need them' (2005, p 33). This leads them to question whether self-neglect should be categorised as a form of elder abuse

at all within care frameworks. Connolly, on the other hand, makes a number of points to support the argument that it should indeed be, on the grounds of the common areas between them:

> Why is self-neglect of interest to those in the justice system (eg, police, prosecutors, and courts) if it does not involve wrongdoing by a third person? Because it is inextricably linked to other types of elder mistreatment that involve wrongdoing, as demonstrated by the following four points: (1) The line between self-neglect and neglect by others can be murky in terms of when the duty to care and culpability for failing to care for someone else sets in. (2) Self-neglect is believed to be a risk factor for and a consequence of other types of elder abuse. (3) Fears about long-term care too often drive frail older people to stay in environments where they can no longer properly care for themselves or worse. (4) Improving how we identify and respond to elder abuse in many cases also will improve how we identify and respond to elder self-neglect, for example, through better interventions, training, research, and public awareness. Thus, most efforts relating to elder abuse have a direct bearing on self-neglect as well. (2008, p S245)

Indeed, 18 of the 155 included papers link self-neglect to neglect or mistreatment by others. The exact relationship may be complicated. Self-neglect may increase the risk of maltreatment by others but, equally, the converse may occur (Paveza et al, 2008). In one database study of 538 cases referred to the Texas Elder Abuse and Mistreatment team for self-neglecting behaviour, neglect by others was a feature in 28 per cent (Dyer et al, 2008b), with the researchers concluding that self-neglect may be an antecedent to other forms of maltreatment. Lauder and Orem (2001) suggest that the nature of a care relationship, or its breakdown, may prompt self-neglect, but that also responsibility to care for another may prompt the carer to neglect aspects of their own living situation. Choi et al (2009) also suggest that neglect by others may be a feature in some self-neglect cases. Choi and Mayer (2000) acknowledge that, as self-neglect does not involve perpetrators, people may question its categorisation as maltreatment. However, they argue that, as victims of physical, mental and/or cognitive impairments, and being in need of assistance, people who are neglecting themselves should be included in adult protection services.

4.2   Key informants' perspectives on self-neglect and safeguarding

For key informants, the question of whether or not to include self-neglect within safeguarding policies and procedures was significant and one which did not necessarily attract unanimity of views. For one key informant, the distinction between whether or not someone had decision-making capacity was crucial, with the conclusion that, for those believed not to have capacity, action was needed and it should be seen "definitely as a safeguarding issue, even if other people criticise us for doing it". For those with capacity, sound social work practice skills had to be relied on, although this too – staying involved and monitoring the situation, continuing to develop a relationship that might actually create a different ability to make a different decision – could be under a safeguarding umbrella.

'I think without capacity or with some really compromised capacity then it's a safeguarding issue. When you believe that people have generally got capacity, though they might not have good decision making, then it's around being very aware if they have vulnerabilities and you're very clear about that, you start to protect yourself and your organisation and your staff and constantly approach the person in a supportive way, trying to be creative about how you might engage them.' (Key informant)

For another key informant, the relationship between self-neglect and safeguarding arrangements, at a Board level and at a practice level, was emerging as a big theme that had to be tackled. The threshold at which self-neglect becomes a safeguarding issue and/or a risk management complex issue was also an emerging area of practice. It was possible to envisage responsibility to grapple with this area as resting with Safeguarding Adults Boards, but this should be underpinned by national guidance.

4.3 Workshop and focus group discussions on self-neglect and safeguarding

A number of participants pointed out that the definition in *No secrets* excludes self-neglect because it assumes that abuse must involve a perpetrator. Equally, when reviewing local authority documentation on adult safeguarding, most procedures made no reference to self-neglect at all. A few authorities explicitly excluded self-neglect from their safeguarding policies and procedures and a small number explicitly included it. This was a scenario that focus group participants recognised. Thus:

'Our procedures, to my knowledge, don't have any thoughts on self-neglect arrangements at all.' (Workshop participant)

Focus group participants were clear that self-neglect falls outside the *No secrets* definition of abuse and neglect. Thus:

'… self-neglect might be because you have lost capacity to actually take responsibility for looking after yourself and therefore it may be a sign that you need help. Whereas self-harm is where you are perhaps actively hurting yourself because it's a cry for help or whatever it might be, and obviously they define it different ways, but when I started in my current post our training and workforce development officer strongly argued against including self-harm in safeguarding where I wanted to open it up, on the basis that there was no abuser, there was no perpetrator separate from the alleged victim, so when you're having your investigation in your case conference who is it that you're substantiating the allegation against, and it may be an indicator that other people are neglecting someone but they're then self-harming, but self-harm itself isn't a separate perpetrator and how can it be abuse under the *No secrets*…' (Focus group participant)

And from a workshop:

'… certainly the strict definition of abuse in *No secrets* is "by another person" isn't it, so I think some authorities use that very rigidly and say, "well actually

no, that doesn't include people whose behaviour, where they have capacity, engages in behaviours that are causing us serious concerns and therefore they are at serious risk of harm", so some people have drawn a line there.' (Workshop participant)

However, the same participant acknowledged that this was not where their authority had drawn the line, while another agreed that the question of definition was a "bit of a blurred line".

Perhaps not surprisingly then, local approaches to self-neglect varied. In some local authorities, cases of self-neglect were dealt with through safeguarding procedures. In others, cases of self-neglect were care managed. In others, self-neglect came within safeguarding if it appeared to be associated with neglect by a third party. However, for focus group and workshop participants, it was thought important and useful to have some kind of multi-agency framework for deciding whether someone/anyone has a duty of care to someone who is self-neglecting, and workshop participants thought the safeguarding system could provide such a framework. Some examples were given of additional policies being developed, as 'add-ons' to safeguarding, to which all agencies signed up. There was strong consensus that having an interagency process through which to share concerns and run decision making was important in protecting agencies in cases where intervention either could not be made or was not successful in remedying the self-neglect. One such model was a Vulnerable Adult Risk Management Strategy (VARMS), the aim of which was to provide 'a very structured, multi-agency model of intervention and recording of intervention, but [outside] the safeguarding procedures'. This sets up a parallel interagency process to which cases of self-neglect can be referred if an alert is made to safeguarding, and a strategy discussion indicates that there may be a need to respond. The VARMS system is external to adult social care, and not prey to Fair Access to Care Services (FACS) eligibility levels. It of necessity escalates responsibility for the response to, and containment of, risk to a higher organisational level.

Another authority used safer neighbourhood teams:

'What we've also looked at is assigning a social worker to a safer neighbourhood team, so we actually meet with the safer neighbourhood team which comprises of community support officers, the local police personnel, any housing bodies who are actively involved in that area, as a way of forging links. So we can meet these people or give advice and information and we become aware of what's happening in a smaller area. It may never come into the safeguarding arena but we want to take some kind of responsibility for these vulnerable, self-neglecting people and actually refer on or use different resources that we've got already established.' (Focus group participant)

Some participants were concerned about the consequences of procedures failing to discuss self-neglect and had taken steps to reach informal agreements with colleagues about how cases would be responded to. Thus:

'We're struggling as a team at the moment with the people whom we are classing as vulnerable falling through the loop. People who may have a mild

diagnosis of learning disability or they're not ... they don't have a formal diagnosis of mental health or they don't have a formal, physical disability and they're under 65. We're finding a lot of people are actually now surfacing and the thought ... at the moment is that we are looking at safeguarding actually leading with this, just as a way of getting in to see these people. We have discussed with Intake doing joint visits really to see if we can capture these people and undertake a safeguarding/assessment of need in one area. So that's the way we're looking at it at the moment, although it is only an informal arrangement.' (Focus group participant)

This reflects a more general sense of focus group participants keen to ensure that cases of self-neglect did not slip through the net. This could mean that Safeguarding Adults Boards might assume some form of accountability for cases of self-neglect, even when they were care managed or taken through a risk management model rather than safeguarding procedures, in order to ensure that agencies were "making sure that just because they don't happen to fit into a nice little service box, there is a safety net somewhere". It was an example of using safeguarding processes "to actually demonstrate the collective authorities' concern about someone's situation". Thus, in one authority, social workers and/or other agencies might agree a support plan with an individual who was self-neglecting, where safeguarding staff would then monitor whether the person was using the plan agreed with them. Another workshop participant summed it up as the Board, and safeguarding procedures more generally, ensuring good practice at the front line:

'We don't have it as part of our policy and procedures but we have invoked safeguarding procedures where there's an indication of a failure of agencies to properly coordinate support around somebody who as a result came to significant harm. So, a good example of that would be somebody with capacity who was choosing to live at home, had significant pressure areas, was at high risk and ... although she was saying she didn't want any intervention, we felt that there could have been more work done to make sure that that decision was informed, that her decision for non-intervention was informed, so we felt there was a bit too much of a hands off approach in that case. So, it's ... making sure that we're proactive enough to evidence that we've engaged the person around decision making, so that if harm was caused that they would understand what the repercussions would be. For somebody who lacks capacity I guess clearly there needs to be proper care management, and assessing and reviewing on a regular basis, and again I guess safeguarding will only come into play where we felt that that hadn't been done in line with a "best practice" model ... I guess we would see safeguarding as relevant where there's been an omission to act or a failure to act, but it's those cases where people are currently self-neglecting and you're not necessarily managing that under safeguarding, but you're managing it under the model of safeguarding, which is multi-agency working. So ... you use the model of safeguarding, which is working closely together with the partners to work towards ensuring the person doesn't come to harm, but we wouldn't call it safeguarding.' (Workshop participant)

In the same workshop there was general agreement that having a risk management system, located within the broad remit of safeguarding, could ensure that agencies

shared information and monitored cases. It was seen as a way of ensuring collective ownership, "of communicating and of assessing risk". As one participant noted:

> 'The breakdown is that if you have silos and everybody thinks it's not my risk … and you're identifying the problem was a failure of communication and multi-agency working, and it is all the stuff about team around the patient or client … which is very, very core.' (Workshop participant)

This had led one authority to form:

> '… a multi-agent safeguarding hub, where people will share soft information, because of all the cases that we've heard of, in terms of trying to really identify people who are at risk at an early stage…. So, the groups will share information, but then there's an issue that has to be done by agreement between agencies, of sharing that threshold of information at an early stage. And typically, health partners find it more difficult to do that because of the confidentiality of information. So, there are issues again about thresholds of sharing information and under what remit you can do it, so that's a key issue really.' (Workshop participant)

This flexibility in approach was seen as a model for prevention, as reinforcement for a multi-agency approach and inter-professional communication on individual cases, and as useful and long-standing practice, able to respond to risk contingencies of the day.

> 'I think operationally you can actually push safeguarding in a number of directions if you're the coordinator or whatever, by permitting people to come in. Before we had MARACs we used to conduct some of those situations under adult safeguarding because there was no other process.' (Workshop participant)

Indeed, MARAC was referred to approvingly as providing a template worth replicating for tackling cases of self-neglect since it engaged partners in assessing and managing risk, providing:

> '… a tried and tested method of looking at the risk and if the risk reaches the threshold you share information and you safety plan. Now, that gives you defensible decision making because everybody does what they're best at; so we would look at, is there any criminality, is there anything that we can do; the fire brigade would look at, is there a fire hazard, can we go in and do that; social care would look at that side of things and health …. So we are sharing our information and planning in a very quick and easy way.' (Workshop participant)

Therefore, whether or not procedures actually mentioned self-neglect, operationally safeguarding might be seen as the appropriate location where cases could be considered, as one workshop participant explained:

> 'I personally though have the view that self-neglect does need to come in safeguarding actually. I think it needs to come within safeguarding in order to make a decision whether it [any individual case] should come within

safeguarding or not. The reason I say that is there isn't anywhere else for it to go and the whole beauty of safeguarding, the way we do things, is that we naturally get people together don't we, to share what we have to offer, to share information, to share our knowledge and to collectively make a decision and I think that still is the best way. It used to be old-fashioned case conferences that you used to call. I still think that's the best way of managing things, personally.' (Workshop participant)

However, just as some focus group participants had pushed, not always successfully, to broaden the scope of safeguarding definitions and concerns, for example to include self-harm alongside self-neglect, others were worried that this was "illustrative of how the label of safeguarding can become, it feels, almost all encompassing". Their concern, then, became whether the services had the capacity, the resources, to cope effectively with the actual or likely volume of demand. As a result they "did not want everything in safeguarding". Other objections were raised, on grounds both of data protection and of human rights, about the practice of sharing 'early concerns' information without the active consent of an individual who, almost by definition, was not willing to engage with services.

The workshop participants' position on self-neglect can perhaps be summed up as this. In a society where we value people being safe and we seek to minimise the harm or risk they experience, we have to consider whether we should/can do something in cases of self-neglect; and if we conclude we should not or cannot (for example, out of respect for autonomy), then we must be clear why not. This is better done within a multi-agency framework – a point made repeatedly in both the literature and the workshops – and current safeguarding arrangements are seen as offering one such framework.

5 Interventions

Ultimately, whether or not the system envisages self-neglect as part of safeguarding, and whether or not mandatory reporting is in force, there are a number of learning points that the literature suggests which can inform successful interventions. Not surprisingly, given the diversity of the phenomenon, there is little in the way of 'model programs to manage self-neglect' (O'Brien et al, 2000, p 13) as a whole; rather, the research contribution lies more in that it reminds clinicians and social care workers of important considerations to bear in mind when confronted with each individual case and its particular features. It is worth noting, however, that further research into effective interventions is still sorely needed (Banerjee, 2003; Connolly, 2008).

5.1   Assessment

Perhaps most prominent among the recommendations is the emphasis placed on the importance of sensitive and comprehensive assessment. Dick (2006), for example, argues that interventions require an accurate assessment of the client's mental status, partly because lifestyle and personality traits are often involved, sometimes triggered or aggravated by a stressful event such as loss or physical illness. Assessment should include individual health status, family dynamics, depression and/or dementia, cultural beliefs and family coping patterns. Day and Leahy-Warren (2008b) agree that assessment is crucial in evaluating what can be attributed to self-neglect versus underlying illness or disease. Assessment, they suggest, should therefore be multi-agency and multidisciplinary, and components should involve a physical examination, a detailed social and medical history, a historical perspective of the person and the situation, the person's perception of the position, willingness to accept support, observation and self-reporting. Interviewing family members and people in the individual's network may assist in gathering facts and gauging someone's decision-making capacity. Risk assessment should cover observation of the individual and the home, activities of daily living, functional and cognitive abilities, nutrition, social supports and the environment (see also Gunstone, 2003; Gibbons et al, 2006). Observation and interviews with significant others are important because people who are neglecting themselves often minimise their behaviours (Pavlou et al, 2007). Equally, the effects of learned helplessness, of perceived restricted choices and of depression may also have an impact on how individuals present (Bergeron, 2006).

Dong and Gorbien (2006) stress the role of 'comprehensive geriatric assessment' (p 31), leading to a treatment plan. Greve et al (2004) write that psychological assessment is helpful in ruling in or out the presence of dementia and mental ill health. In a later paper (Greve et al, 2007) they propose that personality disorder and/or OCD may contribute to Diogenes syndrome, and recommend thorough psychological assessment for such cases.

Marshall et al (2000) also foreground the need for a comprehensive assessment, in which they include physical and mental state, psychosocial history, functional/ability/disability, social circumstances and substance misuse. Murray and Upshall (2009) stress the importance of assessment and diagnosis because there may or may not be an underlying medical condition to treat. Pavlou and Lachs argue that:

> ... [intervention] should involve a global assessment, which includes detailed medical, psychiatric, functional, and social history [lifelong traits may be unmasked by new problems such as dementia or functional decline], and evaluation of each domain. (2006a, p 841)

This should be done by an interdisciplinary team assembled on a case-by-case basis. Finally, Snowdon and Halliday (2009, p 998) continue the theme of the 'relevance of medical and psychiatric diagnosis', with assessment key to the early recognition of those at risk. Snowdon et al (2007) also foreground assessment because of the complex interplay of triggers and vulnerabilities. Focusing on hoarding, they suggest that:

> ... obsessive compulsions and indecisiveness may be largely to blame in some cases. In others, accumulation of refuse and useless items is attributable to apathy and impaired executive function, resulting from brain disease or mental disorder ... [or] impaired mental or physical capacity to maintain home care. (Snowdon et al, 2007, p 48)

5.2   Detection and intervention

Several papers, in order to establish whether or not a person has capacity, or to understand the elements within a case of self-neglect, propose the use of screening scales and instruments. Indeed, 'the lack of evidence-based risk factors and screening tools' has been argued to limit 'the clinician's ability to detect those at risk' (Dyer et al, 2007c, p 1449). The rationale for their use lies in an increasing population of older people, making it imperative to assess who can live safely at home and to have a means of deciding accurately when to intervene and when to preserve the autonomy of those able to protect themselves (Dyer et al, 2007c).

Burnett et al (2009a) review the Kohlmann Evaluation of Living Skills (KELS) screening tool of older adults' ability to live independently and safely in the community. They conclude that the tool enables an assessment of someone's ability to perform necessary real-world tasks and assists with decision making about what to put within a treatment plan. Dyer et al (2007b, p 1672) propose 'a battery of geriatric assessment measures' including the Mini Mental State Examination (for cognition), the Geriatric Depression Scale, the physical performance test (activities of daily living), the clock drawing test (executive function), the functional activities questionnaire (daily living) and questionnaires to explore health, nutrition and social support. Their screening scale to assess personal appearance and hygiene, functional status and living environment, in testing, appeared promising (Dyer et al, 2007a), enabling the identification of physical and mental health problems, nutrition issues, inadequate social supports and difficulties with activities of daily living (Dyer et al, 2007b).

The development of diagnostic tools to identify the characteristics and behaviours of self-neglect, embracing intentional and non-intentional neglect, have also been reported by Gibbons (2007). Snowdon et al (2007) emphasise the use of standardised rating instruments to:

... document living conditions, physical and psychiatric disorders, sensory impairment, pre-morbid and current cognition, perception of disgust and personality characteristics. (p 48)

Kelly et al (2008) have also reported on the validation of a self-neglect severity scale, which assesses personal hygiene, impaired functioning and environmental neglect. While remaining convinced of the need for an objective measure of self-neglect, further work was found to be necessary to improve the scale's sensitivity and specificity. Naik et al (2007b, 2007c, 2008c) report on attempts to develop screening tools to test capacity, not always successfully, and to validate the KELS. They found that KELS was 'a valid tool for assessing impaired capacity to make and execute decisions regarding safe and independent living' (Naik et al, 2007b, p S84). However, another tool failed to distinguish capacity successfully (Naik et al, 2007c), perhaps because it measured the capacity to understand and articulate choices (decisional capacity) but not the ability to execute them (executive capacity). On the basis of this experience, Naik et al go on to conclude (2008c) that social services workers need to assess basic cognitive abilities, decisional capacity and executive capacity, seeing the development of tools for this purpose as a way of aligning technical precision with legal and ethical principles surrounding capacity.

One paper reported on evaluation of the validity of a range of neuropsychological tests in predicting harm arising from self-neglect (Tierney et al, 2007). With a focus on verbal recognition memory, executive function and conceptualisation, the research found that the tests were useful 'in predicting behaviour of considerable consequence to the safety of these individuals in their natural environment' (p 146) and therefore facilitated the targeting of community interventions.

Lauder and colleagues (2002b) identify three distinctive ways of responding to self-neglect – coercion, supportive/therapeutic approaches and negotiation – and suggest that professional responses are likely to be the product of a range of factors, including professional socialisation and agency working practice (Lauder et al, 2005b).

A consistent message coming through from the literature is the importance of seeking to work through 'consensus and persuasion' (Payne and Gainey, 2005, p 33), with an eye to according the self-neglecting person their individual rights to the fullest extent possible in the situation at hand. 'Care by consent' (Kutame, 2007, p 33) is presented as the ideal here. This should be prioritised not only because of respect for the client's autonomy – although this is of great importance – but also because it is more often than not counter-productive to proceed otherwise. Lauder et al (2005c) suggest that what they describe as 'excessive professional intrusiveness' is more likely to alienate self-neglecting clients than lead to acquiescence with any intervention, and 'punitive' interventions by statutory services may 'frequently exacerbate [...] the initial presenting problem' (Lauder et al, 2009, p 452). Rather,

> ... given that victims are more likely to view offers of help as being intrusive (Longres, 1994), sensitivity and gentle persistence are more likely to be associated with a positive outcome for the victim. (O'Brien et al, 2000, pp 14–15)

Thibault et al (2000) make the point that all too often even simple (although often overlooked) steps may be of great help in building rapport, understanding people's motivations and enlisting the individual as a willing participant in their own care:

> The clinician who is treating such elderly patients must take the time to be knowledgeable about and sensitive to the quality of her/his life situation. Merely asking the question, "Can you tell me why you are doing these things that could eventually cause your death?" may elicit the cause of the behavior. Often the services of a psychologist or social worker may be helpful when the etiology of the behavior is not readily ascertained. (2000, p 31)

More often, however, in an echo of what the workshops and key informants termed "good social work", establishing a positive relationship with a self-neglecting person requires considerably more effort. Frequently there is no substitute for devoting considerable time on an ongoing basis to the gradual development of a positive relationship of trust (Black and Osman, 2005; Lauder et al, 2005a), although this presupposes not only the worker's willingness to do so but also their availability, which may depend on resource pressures, caseloads and organisational priorities (Black and Osman, 2005; McDermott et al, 2009). The focus on relationships, and especially building a therapeutic relationship, is taken up by Day and Leahy-Warren (2008b). This involves a person-centred approach that listens to a person's views of their circumstances and seeks informed consent where possible before any intervention. The range of interventions can include adult protection, geriatric and neurological assessment, occupational therapy, domiciliary care, advocacy, housing and environmental health services and welfare benefit advice. Based on interviews with people showing self-neglect, Kutame (2007, p 169) found that they talked not about self-neglect but about chronic health issues, pain, weakness, inadequate resources and lack of supportive networks. From these interviews various themes have been extracted, including the experience of living with health conditions, perceptions of healthcare-seeking behaviour, sense of mistrust, difficulties with activities of daily living, lack of resources and services, pride in self-sufficiency and connectedness to places and things. It is this kind of understanding that leads Lauder et al (2009) to remind readers that a refusal of services may be because of how assistance is offered, in other words, because of the approach practitioners take.

Dong and Gorbien's suggestion of planning in terms of the 'continuum of available interventions' (2006, p 32) is another approach which holds out the possibility of intervening in the least restrictive way, and thereby working alongside the client as far as is possible. Ultimately, where involvement is guided by:

> ... the principles of self-determination, the presumption of capacity, domain specificity of competence and statutory intervention as a last resort ... (Lauder et al, 2005a, p 195)

the chances of a successful relationship and intervention become much better. Franks et al (2004) also explore successful interventions in four cases and conclude that self-recognition is an important predictor. They also advocate better communication between health and social care workers in order to release information and resources.

The earlier self-neglect or potential self-neglect is identified, the more effective intervention is likely to be. Day and Leahy-Warren (2008a), Snowdon and Halliday (2009, p 997), Lauder et al (2005a) and Reyes-Ortiz (2006) are among those who highlight its importance, as it may prevent self-neglecting behaviour from becoming too entrenched. When such early intervention is carried out sensitively, with an awareness of the importance of a positive relationship with the self-neglecting person, it also may help to head off the emergence of polarised positions that so often comes to characterise how such individuals perceive their contact with health or social services.

If a collaborative spirit is to be infused into the relationship, it is important that the professional(s) intervening should be able to appropriately reflect on their own position and values with regard to the individual who is self-neglecting. Murray and Upshall (2009) warn that value-laden assumptions can affect the interpretations that workers place on self-neglecting behaviour, a consideration echoed by Black and Osman (2005). The latter recommend that recognising and dealing with one's biases and values is a skill that should be developed on an ongoing basis. Meanwhile, McDermott et al (2009) address how workers need to be particularly aware of their own reactions in environments of squalor. Given how extreme these can sometimes be, their personal levels of tolerance for noisome smells or sights may have strong effects on how able they are to work effectively.

If agreement cannot be reached with the individual, it may be appropriate to use legal interventions (Heisler and Bolton, 2007; Pavlou and Lachs, 2008; Snowdon and Halliday, 2009), so knowledge of the law is crucial (Ballard, 2010). There are a number of areas of law reported as being available, among which are statutory instruments that:

> … permit health care workers to compulsory remand to a place of safety, police to forcibly gain access to an individual's home in order that a formal assessment can take place and environmental health departments to enforce clearing of faecal matter and also bathing and disinfection. (Lauder et al, 2005a, p 194)

Legal options may extend to involuntary commitment, appointment of a guardian or court-ordered adult protection services (O'Brien et al, 2000, p 13), the latter two of which may sometimes be useful ways to avoid long-term care placement (Naik et al, 2008b). It is a common refrain in the literature that it is important for those working with cases of self-neglect to be familiar with the relevant legal frameworks operating within their jurisdictions (Bergeron, 2006; McDermott et al, 2009; Murray and Upshall, 2009; Ballard, 2010, p 186), including the legal rights of individuals balanced against community rights, public guardianship and mental health procedures, and public health and environmental measures. Arluke et al (2002) and Nathanson (2009) make the point that in cases of animal hoarding it is also important for professionals to furnish themselves with at least a passing acquaintance with the animal welfare laws.

The most commonly mentioned and most effective way of facilitating this broad knowledge of legal frameworks, as well as of reflecting on one's own values, is seen as being to approach cases of self-neglect in a coordinated, interagency,

multidisciplinary manner (Arluke et al, 2002; Franks et al, 2004; Reyes-Ortiz, 2006; Ballard, 2010). Indeed, Day and Leahy-Warren (2008a) and Dyer and Goins (2000) emphasise that the sheer complexity of the multiple causes that may be at play in any given case of self-neglect renders a multi-agency strategy indispensable, and Heisler and Bolton (2007) argue that the earlier such a network of involvement is put in place, the better the outcome is likely to be. There is no single checklist of agencies that should be considered; Nathanson (2009) points out that in cases of animal hoarding, social and/or health workers will need to collaborate with animal protection workers and public health officials, and should also understand the self-worth and compensation for other disappointments that people may derive from the company of animals, while Snowdon and Halliday (2009) list individual casework and case management, cleaning, medical and psychiatric services, home services, council services, the Department of Housing and residential care among the agencies that may become involved in cases of squalor (in an Australian context). As Pavlou and Lachs (2006a) state, the assembly of an intervention network can only be done on a patient-specific, case-by-case basis. However, care must be taken so that this flexibility does not work against effective interagency communication or clear lines of responsibility (including for costs, which in cases of squalor particularly can be quite considerable) (Franks et al, 2004; Snowdon and Halliday, 2009).

In the UK context, Lauder et al (2005b) call for an explicit framework for interagency practice, including the values which underpin it, to be agreed between health, social services, environmental health, housing and the police. They show (Lauder et al, 2005a) how such multidisciplinary collaboration is much more characteristic of self-neglect cases where there is a psychiatric diagnosis, mental health services are involved and the CPA approach is being followed, although even here they highlight how effective partnership working is sometimes hindered by the lack of real understanding by each agency of the exact roles and responsibilities of the others (Lauder et al, 2005c). Where there is no such diagnosis, responses are more scattered and often more confrontational. Since they suggest that around half of those who self-neglect fall into this category, they call for more thought to be given to ways in which multiple agencies can work together even in the absence of a clearly identified mental illness (Lauder et al, 2005c, pp 323–4, 2005a):

> The presence or absence of mental health diagnosis should not be the sole trigger for service provision. Rather services should relate to the real lived experience and needs of the client, and a modified version of the Care Programme Approach may be equally appropriate where there is no psychiatric diagnosis. The Care Programme Approach provides a clear process for full multidisciplinary care for people who are not functioning well socially and/or who represent a risk to themselves. This process could be replicated across the health and local government spectrum of services for those self-neglecters who do not have a mental illness. (Lauder et al, 2005a, p 196)

Such a multidisciplinary treatment plan may lead to treatment with medication as one of its outcomes, depending on what underlying mental and physical health problems are identified (Al-Adwani and Nabi, 2001; Blagodatny et al, 2007; Galvez-Andres et al, 2007), although this is usually seen as opening the way for social interventions; as Lauder et al put it,

> ... there remains a valid case for appropriate drug treatment for any mental health problem which coexists with self-neglect, although we are suggesting that this should not be seen as treating self-neglect per se. (2005a, p 194)

In keeping with the emphasis above on what is frequently the long-term nature of involvement with people who self-neglect, some authors recommend ongoing monitoring of their situation, the progress of any care plan and the extent of the cooperation forthcoming (Naik et al, 2008b). Tierney et al (2004) particularly emphasise monitoring the clinical aspects of nutritional status, medical condition, presence of infection and adherence to recommendations, although this is particularly in the context of older adults suffering from ill health who refuse medical advice and interventions, which may not be the case of all who self-neglect. However, Lauder et al (2005a) sound a cautionary note, warning that ongoing monitoring as the main plank of any plan to keep the situation stable is likely to be unsustainable unless it is shared effectively between agencies, thus providing adequate support for the workers involved.

While cleaning services are usually an essential part of squalor or hoarding interventions (Franks et al, 2004), they are rarely in themselves sufficient (Lauder et al, 2005a):

> Simply going into the individual's residence and cleaning does not improve the situation; hoarding usually resumes once outside agents leave. (Greve et al, 2004, p 705)

They should therefore take place as part of an integrated, multi-agency plan. McDermott et al (2009) point out that it may be necessary to identify forensic or specialist cleaning firms, because many cleaning companies are unwilling or unable to deal with the levels of squalor with which situations of self-neglect may present them.

Often a key area for intervention is assistance with activities of daily living, from preparing and eating food, to using toilet facilities. As self-neglect is often linked to disability and poor physical functioning (Pickens et al, 2006a, 2007b, 2007d; Dong et al, 2007b, 2009b, 2010a; Naik et al, 2007a; Poythress et al, 2007; Naik et al, 2008a), such an approach can yield significant improvements in self-neglect (Griebling, 2010). Naik et al recommend that:

> ... interventions should target specific impairments either by supporting the deficits of the vulnerable elderly person (eg, treating symptoms of depression, providing a transfer bench for the bathroom) or by reducing the effort needed to accomplish a task (eg, engaging a home-health nurse to assist with medication management, designating a proxy for financial affairs), following a strategy used to address other types of functional impairments. (2008a, p 11)

Even aside from its direct effects on levels of self-neglect, such practical assistance is seen as being of great value in gaining acceptance:

> Often it is simple practical support in the form of shopping and cooking which produce improvements and create the context for the development of a trusting relationship in which the client engages in the therapeutic process. (Lauder et al, 2005a, p 196)

In the absence of 'magic bullets' in intervention, the literature would caution against underestimating the value of this kind of input.

There is a view in the literature that sometimes transfer to a more structured environment may have to be considered to ensure the health, safety and general wellbeing of an individual (Blagodatny et al, 2007), although there is an emphasis on the least restrictive intervention (Dong and Gorbien, 2006). If the individual does not wish to move into care, there is evidence that day hospital attendance might be an acceptable compromise, and sometimes leads to both physical and psychological improvement (Ngeh, 2000, p 469). Certainly compulsory transfer into care 'should not be applied simply to ensure hygiene and conformity' (Ngeh, 2000, p 469), but only as a thought-out move to contribute to the individual's medium- and long-term wellbeing. Connolly (2008) draws attention to how perceptions of long-term care facilities and fear of institutionalisation are often a major factor in discouraging older people from seeking input from services, and may even lead them into situations of self-neglect in preference to such a course. Over-hasty moves to impose it on them are seen as likely to exacerbate this tendency.

As psychological factors are commonly cited in the aetiology of self-neglect, one could imagine that the use of psychological therapies might be effective. However, there is little evidence reported either for or against this proposition. Snowdon and Halliday suggest that in some cases a cognitive-behavioural approach to hoarding is useful (2009, p 998), and Fraser (2006) – in a paper describing the application of three psychological theories to elder mistreatment – offers a case study illustrating how cognitive analytic therapy can be applied to reframe cognitions in order to resolve self-neglecting behaviour. Thibault reports on a behavioural intervention to reduce self-neglect behaviours (2007). The intervention was found to be successful to a clinically significant degree and to be maintained for at least three months following the end of treatment; however, only three cases were included in the study. Thus, although the model (with three aspects, incorporating the loss of reinforcements for life-enhancing behaviours, a decline in the effectiveness of the responses of which they can make use and impairment in cognition which exacerbates the problem by rendering it more difficult to find alternative responses) may have potential in offering a practical understanding of self-neglect, evidence regarding which people may benefit most from it, and under which circumstances, is not yet firmly established.

Finally, Kutame (2007) and Connolly (2008) both make the point that individual interventions, while essential, should not lead us to lose sight of the importance of macro-level interventions in the long run, particularly for older adults. Kutame calls for workers to:

> ... strengthen individual older adults and their families, build supportive communities, and advocate for stronger governmental action to prevent and

address self-neglect. It takes a family, a community, a responsive government, and a society to adequately address the multi-layered and complex problem we refer to as "self-neglect" if we are to protect and preserve our seniors. (2007, p 170)

Connolly (2008), meanwhile, puts forward the suggestion that at least some self-neglect occurs because of the fear that long-term care facilities inspire in many older adults and their consequent desperation to avoid any contact with services or professionals that could lead them down that path. She argues that greater efforts to improve these facilities and hold them to account for poor quality care might do much to redress the situation, as – in a wider perspective – might greater state dedication to prevention and intervention.

5.3   Key informants' perspectives on interventions

Building a relationship with people who self-neglect, whether or not they have capacity, was given considerable emphasis. For key informants, as for focus group and workshop participants, the intervention that was necessary was often described as "good social work". By the same token it was seen as unacceptable for staff to say that they wouldn't work with somebody who had the capacity and chose to self-neglect. What was needed here was general social work, relationship building, at the very least careful recording, supporting staff and trying regularly to make contact with that person. Besides demonstrating a general duty of care, it was also a way of risk managing one's own situation as an organisation. So:

'You need to keep approaching the person but there are some people who will always resist you and will have the capacity to resist you and their self-neglect is a way of taking control over their own death to some extent and the way that they will manage perhaps the only thing they've got control over in their lives and they have a right to do it. But you have the responsibility to support your staff so that when they die it's not the guy who didn't get in through the front door and didn't do anything about it who is to blame.' (Key informant)

Responsibility was also seen to be multi-agency, with housing officers, district nurses, voluntary agency staff and community members taking an interest.

Key informants were also somewhat critical of the current legal rules. Thus:

'I think the legislative framework isn't there with strength. It's there in certain circumstances with certain criteria.' (Key informant)

There was also a view that learning from these extreme and complex scenarios was not being maximised from self-neglect practice and from serious case reviews. Moreover, there were concerns about how to respond to self-neglect,

'... not only because of the legislative framework but also because of the resource issue, because a lot of people become vulnerable through self-neglect who wouldn't meet service eligibility criteria and therefore the volume of initial

assessments, you know, if you had a lower threshold, would be greater. So there is a kind of feeling of potentially being overwhelmed by this.' (Key informant)

Capturing all these points – about capacity assessments, the need to understand the detail and meaning of an individual's situation, the utility of the current legal rules, social work practice and resources – is the following experience told by one of the key informants.

'You come across it all the time and I've experienced it personally. The combination of people who are either terrified of losing their independence or terrified of losing their relationships, or terrified of state intervention, together with a state process that is desperate to apply eligibility criteria and find reasons not to support people, is just lethal. My mum, when she had a community care assessment when she was 96, she thought it was a test so she didn't have to go into residential care; she told them she was still driving and they wrote it down, which was completely and utterly … she couldn't even get to the other side of the room, but it was just like "oh you're saying it's all fine, thank goodness, we can go away".'

5.4   Workshop and focus group discussions on interventions

5.4.1   Values

Focus group participants struggled with how practitioners should intervene in cases of self-neglect. Sometimes the discussion was framed explicitly in the context of values, ethics and capacity. This might be to emphasise that self-neglect should not be included within safeguarding procedures or to limit the nature of the intervention because of human rights preoccupations when individuals have capacity. Thus:

'When they've had capacity and they've actually come into, only on occasions, a safeguarding strategy, we have not been able to put in any services because of human rights and respect. You've got the personalisation agenda but what we have looked at is if there are any safeguards, because we know that person is going to die. So we formalise that – and it might be that they periodically visit a GP and the GP's able to monitor – but only feed back if necessary on significant issues, whatever we've raised in that forum. So we'd monitor that way but we can't infringe in their private life, we can't do anything.' (Workshop participant)

A position informed by values clearly shines through this comment:

'I value the fact that people have got the right to make their own decisions, including taking risk or live in a way that I wouldn't. So that is a fundamental part of the value system that really underpins safeguarding for me.' (Workshop participant)

From this perspective, focus group participants were noting a move away from paternalism towards personalisation and individual choice, and saw dangers in creeping back towards a more interventionist orientation. The following quotation is not atypical:

'There is a real risk around self-neglect that we drift into a place where we think we have the right to tell people what to do. And there's a tension there, where we think we know what's best, it's the professional gift model of social work or social care, where we think we know what's best, and because people make choices and decisions that we don't think are acceptable, that we would want to make, we try and prevent them from doing that and there's a danger around the human rights legislation aspect of that.' (Workshop participant)

Alternatively, there might be some unease at how values and definitions of capacity were being used to deny people intervention. Thus:

'I think there is a major issue of people out there, in services, getting mixed messages about the Mental Capacity Act and the personalisation agenda because we do have to undertake risk, but it's about when does that threshold change to meet the threshold for safeguarding and I think there are many professionals who are training who are saying "well if they have capacity, they have choice and it's risk, you don't have to do anything". I think they need to have embedded in there the safeguarding thresholds otherwise we're going to get more and more people slipping the net because that clear message they're hearing is "they've got capacity".' (Workshop participant)

At other times the discussion was framed more generally. Thus:

'Some of the links with self-neglect are about how we support people to manage risk in their own lives, and if you're moving to a person-centred way of working in health and social care, then if all you're worried about is other people being horrid to a person, other people abusing someone, other people neglecting someone, then you're taking an approach where you are looking after somebody rather than helping them to look after themselves. Whereas, self-neglect is about helping people not to neglect themselves and it's much more person-centred, and it's about what are the risks in your life posed by other people, posed by your environment, posed by yourself, and actually that whole self-directed life, self-assessment, self-directed support, just taking that approach where you come from a philosophical point of saying, "Each of us has the right to be in charge of our own life". How you then structure safeguarding to enable that in here, in your head, how you think of it conceptually, so that you're supporting that person to be safe from harm, isn't about other people looking after them.' (Workshop participant)

Yet it remains a challenge to find a balance between empowerment and what is expressed as a duty of care, which is equated with a more risk-averse approach. The temptation to swing between two polar positions, rather than holding the tensions between them and negotiating a balance in each individual situation, lies behind the following quotation:

'... because we've been criticised in the past, that both health and social services have been risk averse, in the new kind of personalisation agendas it's almost as if that terminology about formally assessing risk, we're avoiding it ... you look at the new documentation, the new guidance, it's very much about self-

determination, a person's intentions, meeting their needs flexibly and kind of losing sight a little bit that fundamentally one of our roles in my view should be keeping people safe, you know, and it's almost as if we're a bit wary and shying away from those core things which we've still got to do. We've still got that duty of care to people and yet it seems as if, certainly when I've been involved in personalisation, it wasn't discussed at all, which I found quite surprising really.' (Workshop participant)

Working in a person-centred, empowering way was seen as needing a flexibility of response. Sometimes using the support of a neighbour might be appropriate, at other times drawing on one professional's relationship with an individual, and at still others, using the whole multidisciplinary team.

References to values and ethics predominantly focused on respect, autonomy and choice. A Kantian perspective was, therefore, fore-grounded and there was little mention of what other ethical paradigms, such as an ethic of care, might have to contribute to understanding dilemmas surrounding capacity and intervention in cases of self-neglect. The literature surveyed also highlights a similar tendency on the part of professionals to see ethical issues in terms of autonomy, self-determination and respect.

5.4.2 Assessment

For others, intervention was seen in the context of risk assessment, namely: 'we need to capture these people who are saying we don't want this service and you have to look at that risk'. This could mean that cases of self-neglect would be dealt with by safeguarding specialists because the people who use services did not meet the local authority's community care threshold criteria, despite the risks being presented. Thus:

> '… somebody who wouldn't get into learning disability services or into a mental health service undoubtedly is vulnerable, not coping particularly well. They may be rejecting services and it would … certainly in teams I managed, it would tend to end up in that team because there was nowhere else for it to go. And I think certainly … it wasn't included in terms of formal safeguarding protocols or anything written but I think there was an expectation that those cases, when they came to light, when they were referred, would be worked with or you try to work with them.' (Workshop participant)

However, others were concerned that creating specialist teams might encourage other practitioners and managers to the view that safeguarding was not their business. In another workshop there was a similar emphasis on risk assessment to be able to identify and subsequently monitor actively cases of self-neglect. A number of serious case reviews had criticised local authorities for not having mechanisms through which to judge whether risks in particular cases had been increasing, and for having closed cases on the basis that 'everything had been tried' and circumstances had changed and an individual had died. Multi-agency risk assessment, it was argued, was very significant in capturing "how organisationally we fail or have failed to link together to ensure that we have done whatever we can". A number of authorities had

created mechanisms similar to a MARAC model and were sharing information with a view to assessing and managing risk. As one participant talked about it:

'When you get to the acceptance because everybody has done what they said they'd do, you don't leave it, you still have to review it and every time that person comes to your attention you have to have a process which catches them when they tip into the lacking capacity stage hopefully … when it's low risk you monitor it and you offer the support and you give people the information and as the risk goes up you do more and more interventions. But if they say no and they keep saying no, and they understand the consequences, then you are still there monitoring and ready to intervene if necessary, or ready to offer the support if necessary but it's very defensible. And when we've had homicide reviews where these processes have taken place, actually there is no blame, there is always learning, but actually people were doing the best that they could and there is still a responsibility on the individual, which is where it's different to abuse inflicted on someone, you can abuse yourself.' (Workshop participant)

In one authority this type of procedure, for multi-agency sharing of information, followed a RARA model – seeking to remove, avoid, reduce and/or accept risk. Another authority had established a 'hard to engage service' with the aim of seeking to work with adults who self-neglect and reject assistance. The purpose of these initiatives appeared to be to give explicit consideration to what could be done, even if no action ensued:

'… very often there's not a lot you can do in terms of enforcement, but they'll look at the impact they have on other people. But you do come to the conclusion that some people just live a peculiar way of life and what they can do is, they can flag up someone who is really not very well looking after themselves and not good at that, but that's about as far as you can go, but at least, at least they have been discussed and flagged up, and if it gets worse then it's escalated up a little bit. But it's just the fact that someone has taken the trouble among a group of agencies to consider it and see if there isn't anything they can do.' (Workshop participant)

Other participants speculated that a quality of life assessment might be useful, especially if the problem of whose standards were being used could be addressed. For others, a key within assessment was looking to understand the meaning, function or explanation for an individual's behaviours.

The multi-agency and interdisciplinary nature of cases was also recognised, whether or not adult safeguarding procedures formally included self-neglect. Where individuals were refusing most offers of assistance, it might be possible for one professional, such as the GP, to monitor the situation.

'The other thing we do obviously is use other means so you know, the housing officers, so it's about good links with housing and others. So it might be enforcement which I know is being taken round people that are living in squalor and that approach, so in some ways it mirrors the procedures. It is certainly multidisciplinary, often multi-agency. There's a mental health side obviously

which sometimes is appropriately received and given support, but not formally part of the procedures.' (Workshop participant)

Discussion often returned to cases where individuals refuse assistance, despite the risks involved, and where outside commentators, especially in the media, might argue that something should have been done. The key here was felt to be documentation of how the risks had been evaluated and how the values of independence and self-determination had been weighed against impact on self and others. Where safeguarding procedures were not used to discuss how to respond to a person who withdraws, participants pointed to MARAC as an example of a multi-agency process where difficult dilemmas surrounding rights and risks could be worked through. However, not everyone necessarily felt totally comfortable with this approach because of the value position it reflected:

'I still do worry about that drift over towards a separate body making ethical decisions about how people should live their life and it must be really sensitively managed I think.' (Workshop participant)

5.4.3 Thresholds

The operation of FACS criteria and the restriction of preventative services were identified as meaning that someone with care needs might not receive assistance until their situation had deteriorated to a point of self-neglect. The operation of thresholds could also make it difficult to identify cases that could then be processed through the MARAC type processes described earlier. As one workshop participant observed:

'What we've been trying to do is identify some of those triggers to get the staff to flag it up in the first place, to get it above the threshold so that you can actually flag it up to discuss it. So, there's something about the volume of cases as well as the fact that quite a lot of frontline staff are not necessarily taking ownership to escalate concerns and we've been looking at a model, with our PCT [primary care trust] colleagues, to see how we can use specific triggers to get it up into an escalation process in the first place, so that you can then decide whether it warrants further intervention or not.' (Workshop participant)

The same theme can be detected in the following concern about whether cases of self-neglect were being appropriately identified.

'While there are quite critical issues around the social work, competency and confidence, very often it's the step before that that I think things go badly wrong, particularly the way a lot of social services departments are being set up or have been restructured and the access points around the understanding about what self-neglect is. You may have call centre staff dealing with that, who have minutes to do their screening, could quite likely be sending it onto the wrong teams, to the wrong place, that if they don't meet FACS they then end up getting signposted or navigated to, sometimes appropriate but not always appropriate, services. And I think a lot of people do get lost ... things weren't being picked up at that point of contact, and there was a real lack of

understanding about what constituted self-neglect, and that push to get people … because it's service avoidance, it's getting people away from social services.' (Workshop participant)

5.4.4 Law

Some local authorities had considered the use of Section 47 of the National Assistance Act 1948, but had backed away from seeking to implement its provisions. No cases were found where Section 47 had actually been used although in both the focus group and workshops participants shared cases where coroners had criticised local authorities for not using Section 47. Indeed, examples were given of where people were living in very self-neglectful situations but had been judged to have had capacity, and professionals had concluded that they had little legal authority to intervene. In such situations, at least one authority was considering the establishment of risk assessment panels, outside of safeguarding procedures, where such cases could be discussed. However, some participants were concerned if representatives of people who use services and carers were excluded from such panels, especially in the context of personalisation and, therefore, the co-production or at least sharing of decision making.

The focus in discussion was on Article 8, rights to private and family life, which was usually interpreted as restricting intervention. The qualified nature of this right, a public authority's duty to positively promote people's rights and the interface with Article 2, the right to life, hardly featured at all. Equally, Section 47 is primary legislation and therefore may be used by public authorities, even if it is seen to contravene Article 8. Were such a case then to be contested in court, the public authority would have a defence that it had acted according to primary legislation. The court would then have the option to declare Section 47 incompatible with the Human Rights Act 1998 and the European Convention on Human Rights. At the very least, therefore, this legal literacy indicates that public authorities must have a process whereby they can be shown to have given Section 47 due regard in any decision-making process. One view expressed was that Section 47 was being avoided because of concerns rooted in ethics about the provision. Another was that its interface with the provisions of the Mental Capacity Act 2005 was unclear and that the framework in the 2005 Act might override the 1948 provisions.

It was recognised that intervention was possible where other people's wellbeing was affected. For example, one workshop participant noted that environmental health officers would intervene if vermin were found. Thus, the response to self-neglect could be constructed by its social situatedness, which allows consideration of the risks to other people. One person's human rights might have to be balanced in terms of the legality and ethics of an intervention with another's self-same rights:

'Just being very practical again, many of the cases of self-neglect that I've also been aware of, and I bring hoarders into this, is that actually if they're hoarding there are other issues as well, aren't there, rats or risk of fire and so on. So you're never looking at a situation in isolation to what impact it has on others … a gentleman that I dealt with some years ago, because he was defecating in the bath and it was all spilling over, it was going into all of the flats downstairs etc.

So just to remind ourselves that we don't usually have somebody in the middle of a field who is self-neglecting.' (Workshop participant)

The complexity of the legal rules, and especially of the interface between human rights legislation and the duty of care, surfaced periodically in all workshop and focus group discussions. In one workshop, part of the discussion revolved around whether, where an individual has capacity and is refusing assistance, it is legitimate to convene the multi-agency safeguarding network to discuss the case. For some participants in this workshop it "felt like pushing the boundaries sometimes", with the lack of certainty about what was permissible in law leading to "us trying to protect ourselves in the circumstances". One person concluded as follows:

'I suppose, this is where I draw the line, there is a difference between getting everybody together to come to that conclusion and to make sure that whatever the line is, people are helping in whatever way they can. So there is a difference between getting people together to make that collective decision and deciding what actually you need to do, and actually acting and doing something against their free will. So I would definitely go with one bit, I may or may not go with another bit, but I don't know. I know there's different legislation but we do actually section people too and there are very thin dividing lines there too. It isn't black and white is it, it isn't very clear sometimes.' (Workshop participant)

And yet, in the same workshop, another participant saw this question of convening the network differently:

'I think the definition of abuse is an interesting one here because it says that it's a breach of human rights by any other person and persons. The Mental Capacity Act tells us almost what people's human rights are. So if they've got capacity, they've got a right to make the decision and we need to go along with that. My take is that if we override that because of our own fear that we'll be held to account for something that we had no control over maybe, and breaching their rights again in terms of what our response is to self-neglect, I just think that sometimes we regrettably, by overruling somebody's decision, will be breaching their human rights to make decisions. We need to very clearly weigh up why we're doing that because otherwise I think we should maybe say we're overruling this person, it's a human rights breach, how do we deal with this? It's a real grappler, and I'm not saying what's right or what's wrong, I'm just saying that the law that we've got, on the one hand we're getting told people who have capacity can make decisions for themselves, but on the other hand we're held to account when we're allowing people to make risky choices. So I think other than advising them what there is out there and helping them to come to a decision that will safeguard them better, I don't think we can actually go to a strategy meeting and discuss that behind closed doors and behind that person's back, because I would feel we're breaching their human rights.' (Workshop participant)

In another workshop the complexities of the legal rules surrounding information sharing were discussed. This focused in particular on healthcare and medical professionals and the degree to which they felt able, in law, to share information without an individual's consent and the impact this could have on case monitoring.

It is perhaps not surprising, therefore, that research on adult safeguarding has found that the law is experienced as both difficult to understand and difficult to implement (Perkins et al, 2007; Pinkney et al, 2008).

There was speculation about the impact of the Law Commission's adult social care law proposals in terms of creating a legal framework that could give more room for manoeuvre – at present "it's easier to protect the dogs".

5.4.5   Real social work

In all the discussions participants returned to the idea that self-neglect cases required interventions founded on basic social work skills. Complex case management, which these cases often required, had to be accompanied with skilled professional practice, including an emphasis on relationships over time, trust building and ongoing assessments. The following comment is typical and a reminder of how targets and performance indicators are seen as having undermined the essence of social work.

> 'I certainly hold the view that these cases that we're talking about are classically the ones that should be actively case managed on an ongoing basis and shouldn't be this "target – assess – review – close" under the care management process, do you know what I mean? And I know we're all guilty and we all get pressure about that, to meet our performance indicators, but I think as a core of our experienced workers that should be their caseload really. It should be about monitoring these vulnerable people that perhaps are not keen on engaging with us and don't really want any service provision from us. But I think it's switching it round a bit and considering that old fashioned concept of social worker time being a service and a resource as well that we could use.' (Workshop participant)

And

> 'I think that's a really valid point because as a manager you can feel as if you're stuck between a rock and a hard place and obviously there is a need and a pressure to allocate work, but I also know, certainly managing an Intake service at one point and a locality team, there are a certain number of those cases where you've got to social work them which is – okay what does that mean? It actually means I suppose risk management in one sense. It means actually trying to connect and build a relationship which doesn't fit neatly into sort of the care management process, you know and yet it hasn't ... I think for most departments you feel like you're not ... somehow you're not doing the job properly if you're allowing this to go on. I'm old enough to remember, you know, sort of pre-community care where that's what social workers did. Okay you can criticise that roundly but I do think there's a place for it in terms of actually these particular cases.' (Workshop participant)

Similar themes emerge from the following quotation too:

> 'I mean that implies a different approach to what I think tends to be, inevitably, perhaps a bit of a mechanistic approach to risk assessment, which is a certain number of boxes are ticked and this is inevitable to a certain degree I think,

you know. So therefore this person is actually medium or high risk but I think in terms of actually engaging the person, saying "okay what's your view of your risky behaviour or your self-neglect?", you know, there is a strong case for engaging, as much as possible, on a one-to-one basis with that person but I don't think we approach it in that way quite a lot, you know.' (Workshop participant)

It was these core skills, especially of good holistic assessments and good risk assessment, that were seen as enabling practitioners to avoid interventions that would actually make matters worse. Cases were described of people with dementia being transferred from home to hospital, with their situations and skill levels then deteriorating rapidly, or of older people who lost their remaining skills to live independently because of insufficient focus on rehabilitation. These were cases where best intentions had been insufficiently person-centred and where intervention had made matters worse, the outcome of different possible interventions had not been considered or the least restrictive alternative required by the Mental Capacity Act 2005 had not been found. Other cases were described where practitioners from a variety of professional backgrounds had drawn on skills such as relationship building to create situations where they could offer support in a timely way, working with and through someone's confusion, depression, loss of energy or wariness.

Again, on the theme of core social work skills, participants mentioned the potential perverse impact of performance indicators on what was looked for, questioned and seen in cases. They referred to the centrality of interviewing, investigation and assessment skills, picking up clues and expressing curiosity, alongside interpersonal skills. These skills could be better developed and used in an organisational context where service provision was oriented towards supporting people and monitoring situations, where teams could engage in learning from difficult and demanding cases, and where managers were not dismissive of frontline staff but rather encouraging skill development and the sharing of involvement in complex cases to prevent loss of confidence or learning from training. Some participants considered that social work had become deskilled. This concern is most clearly expressed in this quotation:

'Social work has been deskilled by 20 years of care management and … some of this, the risk assessment, the risk management, we're in a place where we now have to almost retrain some of our staff to do this, and that underlying this the challenge is not about, do you have the right tools, it's actually do people have the confidence and the competence to do the job which is about safeguarding vulnerable people. It's really as simple and crude as that.' (Workshop participant)

The emphasis on skilled professional practice was seen also as located within an inter-agency framework, which included a 'whole multi-agency knowledge base', and where the exercise of skilled practice was dependent on the actions of others. Attention was drawn to investigations into serious case and agency failures where:

'… it's been that actually people don't share their knowledge base, not just of the case, but of their background knowledge and legislation that they can bring and so that the things can work together. Most of the cases have failed because

of that lack of discussion and communication at an early stage.' (Workshop participant)

5.4.6   Recording

Focus group participants stressed the importance of recording, especially in cases where, following a mental capacity assessment and a safeguarding strategy meeting, an individual had refused assistance. Recording was also important so that authorities could demonstrate that a proper process had been followed and that they had acted reasonably and proportionately. In situations where coroners were seen to be wanting to apportion blame for a death, believing that some agency should have intervened, good practice suggested having an audit trail for what options were considered in a case.

Regardless of whether an individual had capacity, with agencies then having the right to make professional decisions, it was thought important that there was a clear process for capturing the decision-making process, and the determination of when and how intervention might be made, and by whom. Equally, with individuals who had decision-making capacity, there had to be a process for capturing the evidence of how agencies had properly assessed that capacity, including someone's understanding of the potential repercussions of their decisions, and had tried to assist. This was seen as "defensible decision making".

6 Concluding observations on self-neglect

What weight can be placed on the self-neglect literature that has been reviewed? Some researchers have used large samples and investigated several lines of enquiry at the same time (see, for instance, Abrams et al, 2002; Burnett et al, 2007a, 2007b; Pickens et al, 2007b; Choi et al, 2009; Dong et al, 2010a, 2010b). Some studies have used matched controls (see, for instance, Dyer et al, 2007a; Naik et al, 2007a, 2008a). Some samples also explore the relationship between ethnicity and self-neglect, although almost exclusively in a US context (see, for example, Dyer et al, 2007b; Dong et al, 2010a, 2010b). Most of the empirical studies reported in this review critically appraise the strengths as well as the limitations of the research on which they have reported and, while variable if not confusing evidence about correlations has emerged, the literature does reinforce the importance of a multidimensional and multiprofessional assessment of needs and of the impacts of self-neglect. Early detection, prevention and intervention strategies will be informed by such an assessment (Lauder et al, 2005a; Dong et al, 2010a, 2010b). Indeed, the importance of inter-professional working emerges quite strongly, encompassing housing and environmental health officers alongside health and social care workers (Lauder et al, 2005a, 2005c), given that self-neglect may be triggered by and then exacerbate physical and mental ill health, impairment of daily living skills and social isolation. There are considered reviews of values, ethics and worker orientations, which are derived from case-based research and interviews with professionals (Preston-Shoot, 2001; Black and Osman, 2005; Bergeron, 2006; Dyer et al, 2006a; Day and Leahy-Warren, 2008b). Guidance on practice, including therapeutic interventions, has also been published (Bozinovski, 2000; Fraser, 2006; Buckingham et al, 2008; Ballard, 2010), some of it drawn directly from interviews with practitioners (see, for example, Gunstone, 2003; Harbison et al, 2004).

Nonetheless, Lauder et al (2006) have concluded that research has yet to provide evidence-based interventions. Indeed, the review has not uncovered an empirical longitudinal study into one or more methods of intervention in a representative sample of self-neglect cases. Rather, Hazelton et al (2003) are not atypical in locating their analysis around a single case study. There are other limitations too within the published literature on self-neglect, which sometimes the authors openly acknowledge (see, for example Kutame, 2007; Pickens et al, 2007a). Some empirical studies have used convenience and/or small samples (Gunstone, 2003; Franks et al, 2004; Lauder et al, 2006, 2009; Filippo et al, 2007), which limits the degree to which findings can be generalised to a wider population. Not all samples have been ethnically diverse (Tierney et al, 2007; Burnett et al, 2009a).

Studies are sometimes based around case file audits, which raise the dangers of reliance on written records, and referred groups, which may differ from those who self-neglect but are not known to care services (Halliday et al, 2000). This particularly applies where they have been referred to adult protection services and/or where the sample has been drawn from one geographical location, such as in Franzini and Dyer (2008). There is also the reported difficulty of including more severe cases of self-neglect, for instance, when evaluating the usefulness of assessment tools (Burnett et al, 2007b). At other times, vignettes have been used to gauge how professionals might respond (Lauder et al, 2006; Filippo et al, 2007). There is no guarantee, of

course, that this is actually how they will respond in practice. Often there has been no follow-up. In other words, research takes a single snapshot rather than being longitudinal.

The challenge of distinguishing between cause and effect was discussed in Section 2.9 but is underscored here. Halliday et al (2000) are clear that their research design did not allow the direction of causality to be ascertained. They could only report associations. It remains somewhat unclear what the precise relationship is between self-neglect and, for instance, nutrition and vitamin deficiency (Smith et al, 2006; Aung et al, 2007), social networks (Burnett et al, 2006), isolation and depression (Payne and Gainey, 2005).

Not all studies refer to ethics when outlining and evaluating their research methodology (see, for instance, Dyer et al, 2007a; Garcia-Gallegos et al, 2009) while some studies have yet to report the testing of their recommendations in practice (see, for instance, Dick, 2006; Day and Leahy-Warren, 2008b). Where studies draw on a range of literature, it is not always clear how systematically this has been done (see, for example, Dyer et al, 2007c). If the literature on self-neglect is sometimes repeated rather uncritically, so too are definitions. For example, Daly and Jogerst (2003) did not explore critically each of the offered definitions for self-neglect, especially when attributing willfulness and intent.

A number of the key themes above come together in the following quotation where the workshop participant is focusing across how self-neglect is defined and covered in procedures, the assessment of capacity, the legal rules surrounding the proportionality of intervention and what constitutes good social work practice.

> 'We don't have self-neglect in our policy, either including or excluding it. However, there are occasions when self-neglect is actually dealt with through the safeguarding process because for us it's more about whether the person has understanding of the consequences of continued self-neglect. Therefore do they have the capacity to make that decision? So therefore if somebody doesn't have the capacity to understand the consequences of continued self-neglect then it could go down the safeguarding route because of the capacity issue. If, however, they do understand and clearly are able to demonstrate to ... again I'm going to say a good piece of social work, that they do understand the possible consequences of self-neglect and they still choose to do it, then what right do we have to intervene and it is an issue about proportionality, isn't it. It's about how much you intervene and when you intervene and what level you intervene. So it's about ensuring wherever possible a sound support plan to try and change the person's mind, which won't necessarily go down safeguarding [routes]. All those decisions are made at an operational level, there is nothing specific written about it.' (Workshop participant)

The same coming together of themes surrounding the law and being able to give an account of assessment and decision making may be seen in the same workshop participant's follow-up:

'That's why it goes back really to choice of the individual and us controlling people's choices, which is not the same as in children's because the welfare of the child is paramount. We don't have that, so if people choose to sit on a sofa and do what they're doing on the sofa all day, they get pressure sores and finally sepsis, all you can do really is explain the outcome of their actions to them.' (Workshop participant)

In conclusion, the literature provides a range of insights on the concept of self-neglect, identifying the wide range of perspectives that inform the challenges of understanding and intervening in the lives of those whose self-neglect provokes professional concerns. There is, however, no conclusive evidence on causation, or on the effectiveness of particular professional responses. There are key tensions between respect for autonomy on the one hand, and a perceived duty to preserve health and wellbeing on the other. The former principle may extend as far as recognising that an individual who chooses to die through self-neglect should not be prevented from doing so; the latter may engage the view that action should be taken, even if resisted, to preserve an individual's safety and dignity. Human rights arguments may be engaged in support of either perspective.

Capacity is a key determinant of the ways in which professionals understand self-neglect and how they respond in practice. While professional networks are also likely to engage in information sharing about risk and options for intervention, the autonomy of an adult with capacity is likely to be respected, and efforts directed to building and maintaining supportive relationships through which services can in time be negotiated. Capacity assessments, however, may not take full account of the complex nature of capacity; the distinction in the literature between decisional and executive capacity is not found in practice, and its importance for determining responses to self-neglect may need to be considered further.

While in the US situations involving self-neglect fall within the remit of adult protection services, in the UK they currently fall outside the definitions that regulate adult safeguarding activities. Responses are therefore diverse, and may be led through adult social care or through safeguarding procedures, depending on local arrangements. Whichever structure is used, strong emphasis is placed by practitioners on the importance of interagency communication, collaboration and the sharing of risk.

Notes

[1] It is important to bear in mind here that research originating from the US so dominates the literature during the period considered in this review that caution must be exercised in generalising about national tendencies in this way.

[2] ANOS in this report stands for 'abuse not otherwise specified'.

[3] It should be noted that at the time the data were gathered, this had been in effect for only four years, and the provision has now been overtaken by amendments introduced to the Mental Health Act 1983 by the Mental Health Act 2007.

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An asterisk* indicates that the reference forms part of the 160 references included for keywording.

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*Torke, A.M and Sachs, G.A. (2008) 'Self-neglect and resistance to intervention: ethical challenges for clinicians', *Journal of General Internal Medicine*, vol 23, no 11, pp 1926–7.

*Touza, C., Segura, M.P. and Prado, C. (2004) 'Initial conclusions on the design and validation of the "inadequate treatment detection scale" for elders', *Journal of Adult Protection*, vol 6, no 3, pp 4–14.

*Valios, N. (2000) 'Can we help you?', *Community Care*, 2 August, pp 22–3.

Appendix 1: Overview of the literature review

The approach taken

The review of existing literature formed an essential part of this study. The review followed the principles of systematic review in prioritising transparency and replicability at each stage of the review process: searching, screening, keywording and synthesis. The methodology employed largely followed that pioneered by the Centre for Evidence-Informed Policy and Practice in Education (EPPI-Centre) and adapted to social work and social care by scholars at the University of Sussex (Taylor et al, 2006), and use was made of EPPI Reviewer web-based software for data management and keywording of the literature. This approach allows for the consideration of studies that do not meet the exacting methodological requirements of other approaches to systematic review such as the Campbell or Cochrane collaborations, something that was felt to be essential in an area such as this, where it was soon clear that rigorously controlled evaluations were rare. In this way it became possible to include commentaries, theoretical contributions, opinion pieces and narrative accounts, which in the current state of knowledge unarguably have a significant role to play.

Searching

The research questions that shaped the study were used to identify potentially relevant literature across relevant databases. The search strategy consisted of three elements: 'safeguarding', 'adults', and 'boards/procedures' and various synonyms and related terms designed to ensure that the searches did not miss useful material due to shifts in terminology over time. Each element had to be present in the title, abstract or classification of any reference before it would be caught in the trawl; if any was missing, the reference in question would not be returned by the search. The search strategy was individually tailored to the different databases in order to take account of the varying keyword classifications and to ensure the return of manageable numbers of references from each. A full list of the strategies used can be found in Appendix 2.

Six databases were used in the course of the search, in a compromise between breadth, relevance and available resources. These were:

- ASSIA
- PsycINFO
- Medline
- Social Care Online
- Social Services Abstracts
- Social Sciences Citations Index

Screening

Screening strategy

In deciding on the suitability of references for inclusion in self-neglect review, papers were excluded if they:

- were not in the English language, or
- were published before 2000, or
- were textbook chapters, book reviews, or reports of research published elsewhere that added nothing to the original write-up, or
- did not deal with self-neglect, or
- were so inadequately described in the databases that it was not possible to effectively apply other exclusion criteria (this was only used where there was no particular indication that the paper was of relevance).

While it was recognised that there is certainly interesting literature on safeguarding in other languages, from before 2000 and from outside England, the commission of this review focused on self-neglect within a specific policy context – that stemming from the publication of *No secrets* (DH, 2000). It was therefore decided to limit the consideration of references to those that emerged from this environment by setting the aforementioned limits.

Screening results

Initially 193 references were identified for inclusion and the full papers were sent for. A further 13 papers were sourced through handsearching. Of the total of 206, 21 were removed as they were duplicates; it was not possible to obtain 9, either because it proved impossible to obtain the relevant publications or, for some, because the bibliographic details downloaded did not appear to correspond with any source that could be identified despite exhaustive enquiries. A further 16 were then excluded after reading the full article. This left 160 relevant references, 155 of which were keyworded, and 5 of which arrived too late to be keyworded but were nonetheless relevant and have been drawn on in the review. More detailed figures for the different stages of this winnowing process are given in Appendix 3.

Keywording

Keywording is a process through which the content of each reference is examined and coded according to predetermined questions that pick out the points of interest to the review – a template of sorts. Coding the material in this way permits the reviewers to develop a quick reference overview of the approaches, methods, populations surveyed and other characteristics across large collections of literature, a process sometimes called 'mapping' the field.

Initial joint trialling of the keywording template ensured that the review team all shared a common understanding of the approach, and any doubts or concerns that arose during the process were shared with the other reviewers. In this way it was ensured that any ambiguities were dealt with consistently throughout. The full scheme is set out in Appendix 4. To ensure inter-rater reliability 10 per cent of all the included studies were double keyworded.

Synthesis

It is the keywording template that structures much of the synthesis provided here. The diversity of the papers included discouraged the application of quality

assessment criteria to all of them. Consequently the approach taken here is one of narrative synthesis, the main aim being to describe approaches or theories that may usefully inform understanding of the concept of self-neglect.

Categorisation of the literature reviewed

Eighty-nine of the included papers were empirical, drawing on a range of qualitative and quantitative methodologies. Forty-five of the papers were descriptive, often using case examples as an entry into discussing practice dilemmas, decision-making capacity or approaches to assessment and treatment (see, for example Lauder et al, 2005a; Dong and Gorbien, 2006; Pavlou and Lachs, 2008; Ballard, 2010). Eighteen papers were theoretical discussions or literature reviews, for example on squalor (Snowdon et al, 2007), decision-making capacity (Black and Osman, 2005) and alcohol misuse and self-neglect among older people (Blondell, 2000). The final eight papers were an assortment of editorials, letters and short responses to published papers.

Forty-seven of the papers were classified as interpretation in practice, 113 as conceptual. The former category distinguished papers that reported studies where the findings had been applied or tested out in actual practice. In this context, suggestions in concluding remarks as to how the study might have implications for practice were not enough. If a study's findings or argument had not been tested out in some way, the paper was classified as conceptual. Examples of interpretation in practice include validation of a scale (Touza et al, 2004), evaluation of behavioural methods of intervention (Thibault, 2007) and evaluation of the utility of an assessment tool (Pavlou et al, 2007). The preponderance of conceptual papers raises the question of the degree to which this body of research has actually influenced practice. Recommendations found in these papers, if they have been followed up and applied in practice, appear not to have been further discussed in the published literature. Equally, where papers offer advice for practice, this does not always appear to emerge from practice itself but from a reading of the literature (Ballard, 2010) or media accounts (Bergeron, 2006). There are, however, papers that are drawn from the author's own practice or from interviews with practitioners (see, for instance, Bozinovski, 2000; Burnett et al, 2007a).

Appendix 2: Search terms and databases

Note: The searches for this study were conducted alongside searches for a second study relating to the governance of adult safeguarding; there is some overlap between the two sets of literature and for this reason the figures prior to decisions on inclusion in each of the two separate studies are aggregated.

ASSIA (Applied Social Sciences Index and Abstracts)

CSA Illumina

Searched 3 February 2010

1. KW=**adult***
2. DE= **adults**
3. DE= **elder abuse**
4. DE= **vulnerable people**
5. DE= **incompetent people**
6. 1 or 2 or 3 or 4 or 5
7. KW=**protect***
8. KW=**safeguard***
9. DE= **safeguards**
10. DE= **protection**
11. 7 or 8 or 9 or 10
12. KW=**board***
13. KW=**arrang***
14. KW=**regulat***
15. KW=**right***
16. KW=**proce***
17. KW=**manag***
18. KW=**practice**
19. KW=**policy**
20. DE= **implementation**
21. DE= **legislation**
22. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
23. 6 and 11 and 22

Searched 3 March 2010

1. KW=**self-neglect**
2. DE= **selfneglect**
3. 1 or 2

Medline

OVID

Searched 8 February 2010

1. (abus* adj4 adult*).mp
2. (incompeten* adj3 adult*).mp
3. (vulnerab* adj3 adult*).mp
4. disab*.mp
5. POVA.mp
6. 'Vulnerable Populations'/
7. 1 or 2 or 3 or 4 or 5 or 6
8. safeguard*.mp
9. protect*.mp
10. 'Mandatory Reporting'/
11. 'Elder Abuse'/
12. 8 or 9 or 10 or 11
13. arrang*.mp
14. stakeholder*.mp
15. proced*.mp
16. agenc*.mp
17. board*.mp
18. policy.mp
19. 13 or 14 or 15 or 16 or 17 or 18
20. 7 and 12 and 19
21. limit 20 to (English language and yr='2000-Current')

Searched 3 March 2010

1. self-neglect.mp

Psycinfo

CSA Illumina

Searched 16 February 2010

1. vulnerab* within 3 adult*
2. incompeten* within 3 adult*
3. disab* within 3 adult*
4. 1 or 2 or 3
5. safeguard*
6. protect*
7. DE=(protective services)
8. DE=(elder abuse)
9. DE=(living alone)
10. DE=(patient abuse)
11. DE=(abuse reporting)
12. 5 or 6 or 7 or 8 or 9 or 10 or 11
13. policy
14. manag*
15. board*
16. agenc*
17. stakeholder*

18. proced*
19. DE=intervention
20. 13 or 14 or 15 or 16 or 17 or 18 or 19
21. 4 and 12 and 20

Searched 2 March 2010

1. self-neglect

Social Care Online

www.scie-socialcareonline.org.uk/searchp.asp

Searched 10 February 2010

(freetext='adult*' or topic='vulnerable adults') and (freetext='protect*' or freetext='safeguard*' or topic='elder abuse' or topic='adult protection') and (freetext='service*' or freetext='trust*' or freetext='policy*' or freetext='board*' or freetext='agenc*' or freetext='proced*' or freetext='governance' or freetext='arrang*') and publicationdate>1999

Searched 3 March 2010

freetext='self neglect'

Social Sciences Citations Index

Web of Knowledge

Searched 10 February 2010

1. adult*
2. vulnerab*
3. incompeten*
4. 1 or 2 or 3
5. protect*
6. safeguard*
7. 5 or 6
8. arrang*
9. governance
10. proced*
11. agenc*
12. trust*
13. board*
14. 8 or 9 or 10 or 11 or 12 or 13
15. 4 and 7 and 14

Timespan = 2000-2010

Searched 3 March 2010

1. self-neglect

Social Services Abstracts

CSA Illumina
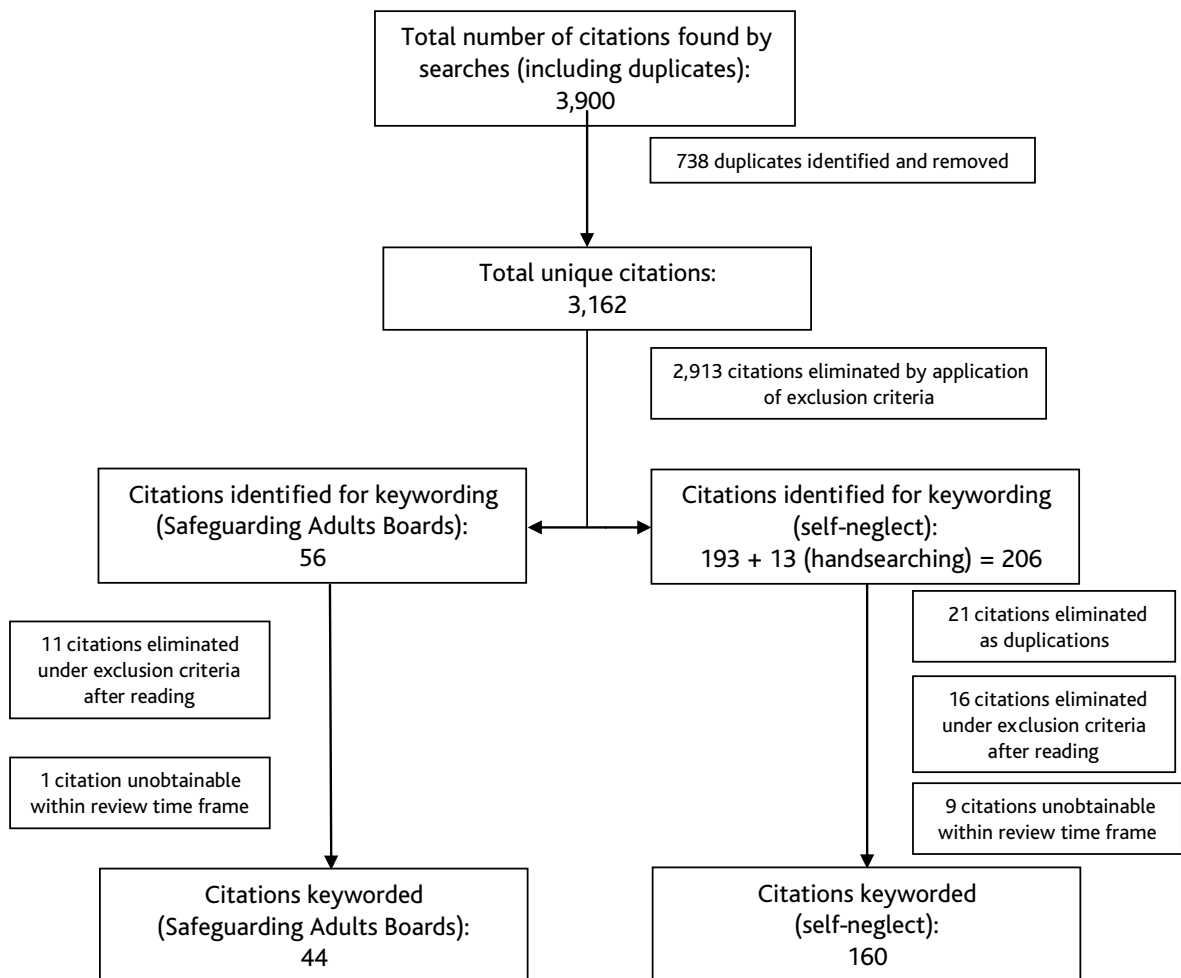
Searched 19 February 2010

1. vulnerab* within 3 adult*
2. abus* within 3 adult*
3. incompeten* within 3 adult*
4. 1 or 2 or 3
5. safeguard*
6. protect*
7. 5 or 6
8. board*
9. train*
10. legislat*
11. arrang*
12. manag*
13. proced*
14. regulat*
15. policy
16. 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17. 4 and 7 and 16

Searched 3 March 2010

1. self-neglect

Appendix 3: Search results: flow chart of process

```
┌─────────────────────────────────┐
│ Total number of citations found by │
│  searches (including duplicates):  │
│             3,900                  │
└─────────────────────────────────┘
            │        ┌──────────────────────────────────┐
            │        │ 738 duplicates identified and removed │
            │        └──────────────────────────────────┘
            ▼
┌─────────────────────────────────┐
│     Total unique citations:      │
│             3,162                 │
└─────────────────────────────────┘
            │        ┌──────────────────────────────────┐
            │        │ 2,913 citations eliminated by application │
            │        │       of exclusion criteria        │
            │        └──────────────────────────────────┘
            ▼
```

| Citations identified for keywording (Safeguarding Adults Boards): 56 | ◄──► | Citations identified for keywording (self-neglect): 193 + 13 (handsearching) = 206 |

```
            │                                    │       ┌──────────────────────────────┐
            │                                    │       │ 21 citations eliminated        │
┌──────────────────────────────┐                │       │      as duplications           │
│ 11 citations eliminated        │               │       └──────────────────────────────┘
│ under exclusion criteria       │               │       ┌──────────────────────────────┐
│      after reading             │               │       │ 16 citations eliminated        │
└──────────────────────────────┘                │       │ under exclusion criteria       │
┌──────────────────────────────┐                │       │      after reading             │
│ 1 citation unobtainable        │               │       └──────────────────────────────┘
│ within review time frame       │               │       ┌──────────────────────────────┐
└──────────────────────────────┘                │       │ 9 citations unobtainable        │
            │                                    │       │ within review time frame       │
            ▼                                    ▼       └──────────────────────────────┘
```

| Citations keyworded (Safeguarding Adults Boards): 44 | | Citations keyworded (self-neglect): 160 |

Search results by database

Database	Citations identified by first search (including duplicates)	Citations identified by second search (including duplicates)
ASSIA	303	48
Medline	348	191
PsycINFO	960	200
Social Care Online	733	44
Social Sciences Citations Index	465	213
Social Services Abstracts	327	68

Appendix 4: Keywording strategy

A.1 Date of publication	A.1.1 2010 A.1.2 2009 A.1.3 2008 A.1.4 2007 A.1.5 2006 A.1.6 2005 A.1.7 2004 A.1.8 2003 A.1.9 2002 A.1.10 2001 A.1.11 2000
A.2 Linked?	A.2.1 Not linked A.2.2 Linked
A.3 Geographical area	A.3.1 England A.3.2 Rest of Britain (please specify) A.3.3 Rest of Europe (please specify) A.3.4 North America A.3.5 Australia/NZ A.3.6 Other (please specify)
A.4 Nature of reference	A.4.1 Empirical (please specify) A.4.2 Descriptive A.4.3 Theoretical (please specify) A.4.4 Other (please specify)
A.5 Reference focus	A.5.1 Conceptual A.5.2 Interpretation in practice
A.6 Subsidiary to mistreatment/neglect by others?	A.6.1 Yes A.6.2 No
A.7 Population focus	A.7.1 Self-neglect in general A.7.2 Older adult A.7.3 Mental illness A.7.4 Learning disability A.7.5 Physical health A.7.6 Other (please specify) A.7.7 Not specified
A.8 Capacity significant?	A.8.1 Yes (please specify how) A.8.2 No
A.9 Population identified from (tick all that apply):	A.9.1 Adult protection services A.9.2 Other medical pathway (please specify) A.9.3 Other social services pathway (please specify) A.9.4 General population A.9.5 Abstractly (ie, in theoretical discussion) A.9.6 Other (please specify) A.9.7 Not specified

A.10 Behaviour (tick all that apply):	A.10.1 General A.10.2 Squalor A.10.3 Lack of self-care A.10.4 Hoarding A.10.5 Diogenes syndrome A.10.6 Frailty A.10.7 Substance abuse A.10.8 Other (please specify)
A.11 Focus of paper (tick all that apply):	A.11.1 Prevalence A.11.2 Definition A.11.3 Correlations (eg, associations with specified medical diagnoses) A.11.4 Detection A.11.5 Relationship with client A.11.6 Intervention A.11.7 Policy A.11.8 Other (please specify)
A.12 Discourse focus	A.12.1 Vulnerability A.12.2 Capacity A.12.3 Rights A.12.4 Empowerment A.12.5 Multiple A.12.6 Other (please specify) A.12.7 Not Clear
A.13 Is self-neglect part of safeguarding? (please give details)	A.13.1 Yes (please specify) A.13.2 No
A.14 Model informing paper	A.14.1 Medical A.14.2 Psychological A.14.3 Social A.14.4 Constructionist A.14.5 Paper is literature review (multiple models) A.14.6 Multiple models (although paper is not literature review) A.14.7 Other (please specify) A.14.8 Not clear
A.15 Definition of self-neglect	A.15.1 Please summarise
A.16 Key findings of paper	A.16.1 Please summarise
A.17 Particular strengths	A.17.1 Please summarise
A.18 Particular weaknesses	A.18.1 Please summarise

Self-neglect and adult safeguarding: findings from research

The research reported here was commissioned by the Department of Health (DH). Conducted between December 2009 and May 2010, it comprised a scoping study of the concept of self-neglect as defined in the literature and interpreted in adult safeguarding practice. The report draws on a systematic review of the literature, workshops with senior managers and practitioners in specialist safeguarding roles, a focus group with adult social care practitioners and interviews with key informants.

This publication is available in an alternative format on request.