



# **A scoping study of workforce development for self-neglect work**

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Skills for Care is the employer-led strategic body for workforce development in social care for adults in England. It is part of the sector skills council, Skills for Care and Development.

This work was researched and compiled by Suzy Braye, David Orr and Michael Preston-Shoot, University of Sussex and the University of Bedfordshire

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## a) Introduction

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### 1.1 Overview of the research

Self-neglect is complex and varied. In England, as in many other countries, there is no standard definition in general use. Consequently consistent prevalence data do not exist at a national level (Braye *et al.*, 2011), making it hard to estimate the scale of the issue. However, qualitative research with social care and health professionals has indicated that self-neglect cases are often practically, personally and ethically challenging for them (Gunstone, 2003; Lauder *et al.*, 2005; Braye *et al.*, 2011; Day *et al.*, 2012).

There is as yet no widespread or definitive approach to workforce development to assist in addressing the difficulties of practice with self-neglect. This study, commissioned by Skills for Care, explores to what extent there is a need and justification for such an undertaking. It reviews evidence from the research literature, relevant serious case review summaries and interviews carried out at five localities within England. The findings add to what is known about the challenges of self-neglect practice and identify key workforce development issues to be addressed. They also identify examples of ways forward already in progress and point to key priorities for the sector skills council, Skills for Care.

### 1.2 The policy context for self-neglect work

Self-neglect has long been something of a 'grey area' (Gunstone, 2003) for social care staff and agencies in England. In contrast to the equivalent guidance in Wales and Scotland, *No Secrets* (Department of Health, 2000) focused entirely on abuse and neglect by a third party, leaving how to respond to the demands of self-neglect largely at the discretion of local authorities and their partner agencies. As a result, some local authorities and local safeguarding adults boards include self-neglect within adult safeguarding procedures, whilst others do not and direct self-neglect referrals through adult social care channels.

In its recent review of adult social care law, the Law Commission recommended that a new duty on a local authority to investigate cases of abuse and neglect should apply expressly to cases of self-neglect (Law Commission, 2011). While the Care Bill 2013 does not include an express reference to self-neglect, the government will clarify the position in a code of practice, due for publication in 2014. The debate has been a factor in raising awareness of the challenges that self-neglect poses to the social care workforce. This study investigates the nature of those challenges and how best the workforce can be equipped to meet them.

### **1.3 The research questions**

The study investigated the following main research question:

#### **How can workforce development equip social care practitioners to work with the challenges of self-neglect?**

Its four key areas of enquiry were:

- the range of social care workforce groups involved with self-neglect
- available evidence on the nature and extent of self-neglect cases coming to the notice of social care agencies
- perceived workforce development needs in different agency contexts
- available evidence on the costs of unmet need in self-neglect.

Finally, the study sought to comment on:

#### **What potential roles could be played by Skills for Care and other relevant partners in workforce development on self-neglect?**

### **1.4 Definition of self-neglect**

In light of the lack of a standard definition of self-neglect, the study used a broad working definition drawing on the existing literature and in accordance with the areas highlighted by Skills for Care in commissioning the research. This definition comprises three main forms of self-neglect, which in many cases will overlap with each other.

#### **1. Lack of self-care**

This includes neglect of one's personal hygiene, nutrition and hydration, or health, to an extent that may endanger safety or well-being. It is recognised that applying this definition in practice requires judgements about acceptable levels of risk and what constitutes well-being. It is just such ambiguity that makes self-neglect so challenging and raises the issue of potential need for workforce development. One of the areas of interest for the study was what different agencies understand by forms of self-neglect that correspond to lack of self-care.

#### **2. Lack of care of one's environment**

This includes situations that may lead to domestic squalor or elevated levels of risk in the domestic environment (e.g., health or fire risks caused by hoarding). Again, it is recognised that in some cases this may be a matter of judgement. What different agencies understand by forms of self-neglect that correspond to lack of care of one's environment was one of the areas of interest for the study.

### **3. Refusal of services that might alleviate these issues**

This might include, for example, refusal of care services in either their home or a care environment or of health assessments or interventions, even if previously agreed, which could potentially improve self-care or care of one's environment.

Although self-neglect is often conceived in the literature as a problem of older adulthood, this study did not exclude younger adults.

While the researchers took their cue from this definition in framing their approach to the study, they remained alert to alternative definitions in operation in practice and discuss these in the report when considering the evidence on the nature of self-neglect cases.

## **1.5 Definition of the workforce**

The agreed focus for this study was the social care workforce, which includes advocates, carers and voluntary workers, as well as employed social workers and social care workers. Self-neglect, however, engages professional groups beyond those working in adult social care. The literature includes consideration of health providers, voluntary sector organisations, environmental health, housing and the police (Lauder *et al.*, 2005a; Braye *et al.*, 2011), to which the fire service may be added. The study therefore engaged with other bodies to the extent that joint working emerged as a key component of existing initiatives. This approach maintained the focus on workforce development in social care, while also enabling the study to identify particular findings on how the social care workforce can most effectively be prepared to achieve effective interagency working.

## **1.6 Definition of workforce development**

The emerging challenges in adult social care require a broad definition of workforce development, which embraces practice, effectiveness and sustainability within systems and organisations, as opposed to a narrow focus on an individual's personal professional development. Maintaining the size and composition of the adult social care workforce, recruiting, skilling, managing and retaining staff, and responding to the policy drive for greater personalisation within service provision all necessitate such an approach (Skills for Care, 2011).

Thus workforce development links individual staff development and learning to other human resource and business activities, such as strategic planning, trend forecasting, workforce planning, performance management and career development (Somerset County Council and SCIE, 2011). It directs organisations to whether they have a learning culture embracing leadership, structures, culture, systems and human

resources that support staff training and development. It envisages supervision as a key tool for support, learning, accountability and professional and service development.

## b) Methods

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### 2.1 Ethical approval

Before commencing work, plans for the study were submitted to the University of Sussex Research Ethics Committee, and ethics approval was granted (University of Sussex Social Sciences and Arts Research Ethics Committee reference ER/SB210/1).

### 2.2 Data collection

Data collection employed two approaches: one based on an evidence review of the research literature and summaries of published serious case reviews and local government ombudsman investigations where self-neglect was identified, the other based on interviews and focus groups with experienced informants in the five localities.

#### 2.2.1 The evidence review

##### 2.2.1.1 *The research base*

This study drew on the results of the authors' earlier review of the self-neglect literature (Braye et al., 2011), which covered publications during the period 2000-February 2010 and searched the ASSIA, Medline, Psycinfo, Social Care Online, Web of Knowledge and Social Services Abstracts databases.<sup>1</sup> The 160 publications finally included within that review were re-examined for content relevant to the research questions of this study.

Given the possibility that more recent literature, published since that study, might contain reference to workforce development, further literature scoping took place. An entirely new comprehensive and systematic search was ruled out given the time available for the study and the likelihood (based on the evidence already identified) that any such literature would not be extensive.

The Social Care Online, Psycinfo and ASSIA electronic databases were searched for relevant literature that had appeared after 2009. Once duplicates, and papers that did not focus significantly on self-neglect were removed, 34 additional studies on self-neglect in general were located in this way. These were added to the 160 identified in the previous review, resulting in a total of 194 studies on self-neglect. However, screening these results against the initial inclusion and exclusion criteria located no literature that focused on self-neglect in relation to the workforce, and little that touched

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<sup>1</sup> Full details of the search strategy employed in that review can be found in the published report (pp. 81-88).

on training. Even in these cases, the focus on training was only minimal and did little to provide evidence of any sort. Hence the decision was taken to repeat screening, using a revised, more inclusive set of inclusion and exclusion criteria which encompassed research from outside England and from the health services as well as from social care. While papers identified in this way did not directly focus on the research questions and setting of interest to this evidence review, they did at least allow the research team to draw on some discussion of research into the extent of self-neglect cases, albeit from a very limited body of research.

Full details of the search process, inclusion and exclusion criteria used are provided in Appendix 1.

### **2.2.1.2      *Serious case reviews***

An internet search of Local Safeguarding Adults Board (LSAB) web pages, coupled with information from research participants, enabled an identification of some serious case reviews where self-neglect had been a feature. A total of 84 LSABs were surveyed, comprising 11 London Boroughs, 33 County Councils and 40 Metropolitan Borough and City Councils. In addition, a review of law reports enabled the identification of cases where the Parliamentary and Health Services Ombudsman or the Local Government Ombudsman had considered cases involving adults who self-neglect. Serious case reviews often conclude with recommendations, not least about training and information sharing, and this was the rationale for including them in this research study.

### **2.2.1.3      *Current Skills for Care guidance***

Current Skills for Care guidance in related fields was also reviewed in the light of this study's findings. The aim was to evaluate how far existing generic guidance (e.g., on risk assessment and mental capacity) might be applicable to self-neglect, and, if the study revealed a need for future guidance on self-neglect, to suggest how they might best be integrated with existing resources. This body of work is discussed in the conclusions to this report.

### **2.2.2      *Interviews and focus groups***

The second approach to data collection used interviews and focus groups in five localities within England. These were selected from the researchers' existing networks established during, and subsequent to, the earlier Department of Health (DH) research, prioritising some of those where explicit engagement with self-neglect had taken place.

The selection of localities was thus not intended to be representative of localities nationally. For the purposes of this research it was more important that they should be able to provide useful information about workforce development because of the

attention they have given to self-neglect. However, the researchers ensured that a mix of types of locality was present in the sample, which comprised two county authorities, one metropolitan borough, and two London boroughs.

First contact in each case was made at senior manager or adult social care lead level, to arrange a telephone interview that would identify the best way of convening participants in the locality. Structures and activity vary from authority to authority, so local advice was important in selecting suitable participants. In each case those involved included managers and practitioners in adult social care (including social work qualified and non-qualified workers), representatives of outsourced, private or voluntary organisations, providing adult social care under contract and key staff from partner organisations (housing, health, police, fire services). The range of participants is shown in Table 1.

**Table 1: Job roles of the participants**

<b>Category of staff</b>	<b>Number of respondents</b>	<b>Comments</b>
Adult social care managers	10	Includes team and service management, and senior strategic roles
Adult social care staff in adult support roles	4	Includes staff supporting, but not carrying out, social work functions
Adult social care staff in specialist housing support roles	3	Includes staff involved in specialist housing liaison and support roles
Partner agencies	4	Includes services distinct from adult social care (e.g., police, health, housing and fire services)
Providers of outsourced supported housing services	6	Includes managers of supported housing, and strategic leads in those agencies
Social workers and senior practitioners	13	Includes adult social work teams and specialist roles, such as safeguarding and mental health
Specialist or advisory roles relevant to self-neglect work	4	Includes mental capacity, commissioning and research services
Workforce development staff	4	Includes officers and strategic leads with a remit for adult social care or

		broader staff groups
<b>TOTAL</b>	<b>48</b>	

Responses were gathered using focus groups and individual interviews in the locality, supplemented by telephone interviews with other key individuals and, in a few cases, written responses. Members of the research team with experience in the field of adult social care undertook each interview and focus group. Discussions were flexibly structured in order to be able to track what was of most interest in each locality. The focus was on workforce development, rather than on individual practice with people who self-neglect. Interviews and focus groups were recorded. The topic list can be found at Appendix 2.

In some cases the focus group and interview data were supplemented by workforce development documents produced by the local authorities. In addition, one key informant, from a national organisation concerned with practice development, contributed perspectives on the transfer of specific workforce development approaches into practice.

In all cases, participation was through the informed consent of individuals invited to take part, and participants were free to withdraw at any stage. The confidentiality of the information exchanged was guaranteed (with the exception of any information indicating unmanaged risk to a vulnerable third party). In line with ethics approval, no individual or agency is identified in this report.

## **2.3 Data analysis**

### **2.3.1 The evidence review**

The literature was mapped and outlined in relation to the four key research sub-questions identified for this study. No studies were identified that directly sought, in the English context, to answer any of these. Use of broader inclusion criteria allowed the review of overseas research and research in health service settings. This at least provided some generally indicative findings that would allow some comment on the issues, although the limited material uncovered is far from being a robust evidence-base. Descriptive narrative analysis was used to summarise the literature, as relevant papers were scarce, and often touched only indirectly on the research questions. This meant that statistical review techniques (e.g., meta-analysis) were not appropriate. Papers discussed were quality assessed on sampling, reviewing the suitability of methods used to answer their research questions, and the extent to which data presented supported the claims made. Because it was necessary to take a flexible

approach to inclusion criteria in this way (i.e., drawing on studies focusing on the health sector rather than social care sector; drawing on studies from outside the UK), conclusions drawn from this evidence review are best treated with caution.

### **2.3.2 Interviews and focus groups**

The content of the recordings of the interviews and focus groups was subject to manual thematic analysis, extracting key issues and themes that arose in the discussions, as well as specific data relating to the four key research sub-questions. Documentary evidence, where available, was used to supplement and illustrate the themes as appropriate.

The original aspiration was to undertake quantitative cost-benefit evaluation of workforce development initiatives in self-neglect work, provided data were available to enable such analysis. Given the lack of a standard definition for self-neglect and the general lack of systems to collect data on such cases, it was perhaps not surprising that the research found no viable quantification of self-neglect work, its costs and its outcomes. The participating authorities are unlikely to be unusual in this respect, as no known national relevant data sets or statistics came to the researchers' notice. The Health and Social Care Information Centre Abuse of Vulnerable Adults (AVA) data collection in England specifically excludes self-neglect.

## c) Findings

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### 3.1 The evidence review

The findings from the literature evidence review are reported using the four key research sub-questions that structured this study.

#### 3.1.1 What is the range of social care workforce groups involved with self-neglect?

##### 3.1.1.1 *Engagement of the social care workforce*

The literature offered few clues as to how different sections of the social care workforce come into contact with self-neglect, or with what frequency. It focuses predominantly on health workers (Braye *et al.*, 2011) and, where the social care workforce is considered, discusses social workers or social work students almost exclusively. Support workers, advocates, self-advocates, volunteers and carers are mentioned only in passing, and the review located no studies that examined the extent of their involvement, or sought their perspectives and experiences of self-neglect.

##### 3.1.1.2 *Inter-agency Collaboration*

This omission stands in contrast to the emphasis that much of the literature places on partnership that crosses the boundaries between the social care workforce and other sectors. Collaboration between social services, health, housing, cleaning services, environmental health and the police is commonly recommended (Lauder *et al.*, 2005a, 2005b; Snowdon and Halliday, 2009). In addition, other agencies such as fire services may have a useful contribution to make in cases where lack of care of the environment is a serious consideration (Lucini *et al.*, 2009).

Partnership working of this kind is a central theme and a generic skill in the adult social care Workforce Development Strategy (Skills for Care, 2011), but there is some suggestion in the literature that it sometimes poses particular challenges in self-neglect. These arise first because health and social care workers may not commonly work with some of the agencies that might have relevant input and so may not think to involve them at appropriate moments (Lauder *et al.*, 2005b; Lucini *et al.*, 2009). Second, the priorities and perspectives that workers bring to self-neglect cases often diverge, in accordance with their agency background (Lauder *et al.*, 2005a) and professional value base. For example, environmental health may take a coercive approach, while health and social care aim to become involved in supportive ways, and housing workers are often most concerned with the tenancy conditions and the state of the accommodation.

While Lauder and his co-researchers also reported examples of supportive practice, where workers had gone beyond the restrictions usually imposed by the boundaries of their roles (Lauder *et al.*, 2005a ), they found that this was less likely in the absence of a formal mental health diagnosis. Their data, drawn from interviews with 31 workers in Scotland, strongly emphasised how sub-optimal joint working led to less effective intervention with self-neglecting clients. They recommended joint training initiatives on this specific topic.

### **3.1.1.3 Community Building**

Two recent studies have explored the question of whether the wider community may play a role in flagging up concerns about self-neglect or working with it. Anderson *et al.* (2010) found that hairstylists in the state of Ohio rated themselves as capable of recognising the signs of self-neglect. May-Chahal and Antrobus (2012) found that members of a community in Britain expressed a willingness to help once they were aware that a problem existed. The conclusions of both studies must be treated with extreme caution on methodological grounds. The former study relied entirely on self-ratings in response to a postal questionnaire and the latter used responses to a vignette. Neither study went further in exploring how likely these declarations were to translate into real actions, but they raise the issue of working with the wider public to ensure that self-neglect, like safeguarding, becomes 'everybody's business.' May-Chahal and Antrobus (2012) in particular suggest that social workers should develop and employ skills in community capacity building to establish a sense of collective efficacy in intervening.

Skills for Care has been considering how it can support community capacity building efforts (Skills for Care, 2010). It recently evaluated a pilot programme supporting local initiatives to develop community skills and neighbourhood workforce planning (Henwood, 2012). There may be lessons to learn from this of relevance for self-neglect, although – as indicated – research into what role the community can play in preventing or mitigating self-neglect is still in its infancy.

## **Summary: the range of social care workforce groups involved with self-neglect**

The literature reveals little about the range of social care workers coming into contact with self-neglect. It has more to say about the importance of successfully involving cross-sector networks, and more recently, the wider community. Here, the research highlights how partnership working is central to social care practice with self-neglect. There is also the suggestion that community capacity building skills may have a role to play, though this has yet to be put to the test in any very meaningful way.

### **3.1.2 What is the available evidence on the nature and extent of self-neglect cases coming to the notice of social care agencies?**

#### **3.1.2.1 *The challenge of definition***

No clear definition or threshold for self-neglect emerges consistently from the literature. One significant difference in approach lies in whether self-neglect should be considered a 'geriatric syndrome' (Pavlou and Lachs, 2006) or a phenomenon which occurs in people of all ages (Lauder *et al.*, 2005a; Gibbons, 2007; McDermott, 2008). While many researchers in North America take the former position (Braye *et al.*, 2011), in part as a result of the structure of Adult Protection Services there, this is less evident in the literature from other countries. It also clashes with evidence from serious case reviews and with our informants' accounts during the interviews of self-neglect cases drawn from all age-groups.

There is also sometimes inconsistency in the range of behaviours that may be classified as self-neglect. These can include lack of self-care with regard to personal hygiene and health, non-compliance with medical advice or refusal of social services, living in unsanitary conditions, certain forms of hoarding or animal collecting, and certain forms of risky behaviour. Again, these were not always treated consistently in the research literature (McDermott *et al.*, 2009; Braye *et al.*, 2011). Moreover, much of this behaviour may present as a feature of dementia, mental illness or substance abuse, or indeed accompanying physical health problems (Lauder and Roxburgh, 2012). They may often be classified under these categories and not appear in the literature as 'self-neglect' at all. Finally, even where there is agreement on the features that may be considered characteristic of self-neglect, there is no standard criterion for self-neglect thresholds that would allow comparison (Spencer-Lane, 2012).

### **3.1.2.2 Prevalence in the UK**

As noted above, *No Secrets* (DH, 2000) provided no guidance on self-neglect for services in England. Although Wales' *In Safe Hands* guidance (Welsh Assembly Government, 2009), did mention self-neglect and listed examples of what it might mean in practice, the researchers were not able to locate published Welsh studies on this topic. Only in Scotland was it possible to identify a study (Lauder and Roxburgh, 2012) that was able to draw on data that recorded with reasonable consistency the nature of self-neglect cases presenting to primary health services. For the most part, therefore, variable or vague definitions within the UK and internationally –even in the USA (Daly and Jogerst, 2003) – have meant that self-neglect has tended to mean what individual researchers wanted it to mean.

This inconsistency in definitions of self-neglect may be one significant factor behind the general lack of convincing studies into prevalence. In England, social care and health services have not generally kept separate data on self-neglect and consequently this review was unable to identify reliable prevalence estimates from the published research.

In Scotland, Lauder and Roxburgh (2012) used primary care data to identify prevalence rates of patients whose diagnosis included self-neglect: 211 per 100,000 population (2005-06), 157 per 100,000 population (2006-07) and 166 per 100,000 population (2007-08). They caution that these figures are likely to be under-estimates, due to the high incidence of service avoidance or refusal among those who self-neglect. Their findings also show that self-neglect occurs in a wide range of age-groups, in contrast with the literature's continuing focus on self-neglect in older adults. They identify a correlation between self-neglect and deprivation, while acknowledging that self-neglect may occur among all socio-economic classes. They highlight that self-neglect co-occurs with a wide range of physical as well as mental health issues. Bartley *et al.* (2011) also carried out a survey of Scottish GPs to investigate the extent of self-neglect among patients on their caseloads, but the validity of this study was called into question by a very low response rate (20.4%).

The only other figures the researchers were able to identify regarding the extent to which self-neglect presents to the UK-based social care workforce were caseload snapshots of small samples of social workers. For example, two studies of approved social worker caseloads both reported that approximately 20% of cases assessed as high risk involve features of self-neglect (Warner and Gabe, cited in May-Chahal and Antrobus, 2012; Davidson and Campbell, cited in May-Chahal and Antrobus, 2012). These studies surveyed 172 and 80 social workers, in England and Northern Ireland, respectively.

### **3.1.2.3 Overseas Prevalence**

Further figures are available on overseas referral rates, but it is not known to what extent these may be comparable to the UK setting. For example, Day *et al.* (2012, 725-743) report that 20-25% of referrals to Elder Abuse Services in Ireland are for self-neglect (see also Clancy *et al.*, 2011 who provided a figure of 20.2%).

A number of studies describe referral rates in the United States, where self-neglect is categorised alongside other forms of abuse and neglect, and extensively tracked. These range from 37% (Teaster *et al.*, 2006) to 65% (Dyer and Goins, 2000) of all cases referred, and up to 89% of all neglect cases referred (Pavlik *et al.*, 2001).

A recent study by Dong *et al.* (2012) is particularly interesting, as it took a population-based cohort approach rather than relying entirely on Adult Protection Services (APS) records. This goes some way to overcoming the risks of selection bias introduced by considering only those individuals who come to the attention of APS. A population of 4627 older adults was mapped within a neighbourhood of Chicago. Trained interviewers assessed participants on 5 domains of self-neglect:

- hoarding
- poor basic personal hygiene
- need of repairs to the house
- unsanitary conditions
- inadequate utilities.

Broken down by age-group, they found that population prevalence of self-neglect in men was 9.5% (65-74 years), 9.2% (75-84 years) and 10.1% (over 85 years); while for women it was 8.5% (65-74 years), 7.9% (75-84 years) and 7.5% (over 85 years). Of the different forms of self-neglect, they found the house needing repairs to be the most common form, followed by hoarding, while inadequate utilities were the least common.

## **Summary: the range of social care workforce groups involved with self-neglect**

No studies were identified giving any large-scale information on the extent to which self-neglect cases presented to social services within the UK. Indicative figures were located based on small samples of approved social worker caseloads, but these cannot be generalised. One Scottish study reported on the extent to which self-neglect cases presented to primary health care services, finding an annual rate of 157-211 per 100,000 population. The authors acknowledge that these figures are markedly lower than the equivalent figures reported from the USA, and suggest that this may be due to their study's focus on primary health care. Many people who self-neglect may choose to avoid seeing GPs or practice nurses (Lauder and Roxburgh, 2012). Consequently, it is open to question how applicable these findings are to social services. Estimating the level of need will remain a difficult task until equivalent studies, or community cohort studies such as that by Dong *et al.* (2012) in the USA, are carried out in the UK.

### **3.1.3 What are the perceived workforce development needs in different agency contexts, and with different manifestations of self-neglect?**

#### **3.1.3.1 Literature on self-neglect**

The literature was more useful in identifying the challenges posed by self-neglect than in offering direction on the relevant needs of different parts of social care workforce. No study made detailed recommendations about this. However, it is possible to glean from the literature general recommendations about how to work with self-neglect. These may offer tentative indications of how future workforce development measures could be shaped. It should be noted that, with the exception of some studies focusing on hoarding, none of these emerged from outcome studies with a control group, or even pre- and post- measures. Rather, they derive from interviews with practitioners, safeguarding leads or service-users.

There are, of course, large amounts of literature offering advice on what to consider when working with self-neglect, or how to approach issues of capacity or ethics, but much of this is not explicitly supported with empirical evidence. Those papers are not considered here.

Recommendations that are made frequently can be grouped under four headings:

- knowledge of self-neglect and the legal framework
- assessment skills
- relationship-building skills and a client-centred approach

- effective multidisciplinary working <sup>2</sup>

### **3.1.3.2 Knowledge of self-neglect and the legal framework**

Gunstone (2003) reported that practitioners found self-neglect challenging and felt they needed a better understanding of the legal framework than they actually had. Although legislation has changed since this study was carried out, and the small number of practitioners interviewed limits how widely its conclusions could be generalised, more recent interviews and focus groups carried out by Braye *et al.* (2011) reaffirm that self-neglect continues to arouse uncertainty for practitioners. There is still limited confidence in workers' approach to capacity assessments and use of legal measures. Greater familiarity with the legal and policy context in which work with self-neglect takes place was thus found to be desirable.

Lauder *et al.* (2005a), based on interviews with 31 workers from housing, healthcare, environmental health and social work, and 6 people who self-neglected, further argue for a greater understanding of the diversity of self-neglect. They focused particularly on the need for awareness of social and environmental factors in leading to self-neglect, rather than too readily assuming that it is necessarily a 'lifestyle choice.' Band-Winterstein *et al.* (2012) interviewed sixteen older people who self-neglected. Based on their accounts, the authors concluded that self-neglect was not necessarily an issue of older age but was related to the person's life history. The overall message was that self-neglect had accompanied the participants into older age. They had experienced frequent transitions, a sense of isolation, and traumatic or difficult life circumstances. Deterioration in their daily functioning had led to involvement or unwilling encounters with welfare services that did not always appreciate their routines or positive traits and capabilities.

### **3.1.3.3 Assessment skills**

Braye *et al.*'s (2011) interviewees drew attention to the importance of thorough assessment of capacity in particular, which they felt did not always happen adequately, again supporting Gunstone's (2003) older findings. Alongside capacity, there is a need

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<sup>2</sup>Interestingly, if allowances are made for terminology and the different workforce sectors being discussed, this schema is quite similar to de Hart *et al.*'s (2009) framework for the competencies required to prevent abuse:

- definitions and policies
- risks for mistreatment
- communication and respect
- development of a cooperative working environment.

This suggests broad parallels between the workforce needs relating to safeguarding and those relating to self-neglect.

for comprehensive assessment that takes account of the multiple factors that may have a role in self-neglect. In Ireland, Day *et al.* (2012) also report that their interviewees (7 senior case workers) emphasised the importance of a sensitive and detailed assessment, while in Australia, McDermott's (2010) 18 interviewees foregrounded careful risk assessment as an essential part of the initial assessment.

#### **3.1.3.4 Relationship-building skills and a client-centred approach**

One of Day *et al.*'s (2012) informants closely linked effective assessment with building up a relationship of trust. Co-operative and client-centred working whenever possible was a recurrent recommendation from the research (Braye *et al.*, 2011). They are emphasised by Band-Winterstein *et al.* (2012), who interviewed 16 self-neglecting older adults in Israel. The key message they took from their data was to see clients holistically and humanistically, rather than under the label of 'self-neglecters.' They argue that it is crucial to see any situation of self-neglect in the light of the life history that has led up to it. Once again this links back to the importance of a comprehensive assessment, and interventions that are sensitive, respectful and tuned to their preferences.

Lauder *et al.* (2005a) suggest that failing to build up a relationship is responsible for the failures of many self-neglect interventions, as clients then barely 'tolerate' service input and may soon come to refuse it, especially if it brings unwanted costs with it. Based on interviews with 10 self-neglecting informants, they suggest that often service refusal is a response to what was perceived as intrusiveness by services in the past (Lauder *et al.*, 2009). However, Day *et al.* (2012) also highlight how building up trust in this way may take sustained input over an extended time period, which agencies may not be willing or able to support (Braye *et al.*, 2011).

#### **3.1.3.5 Effective multidisciplinary working**

The literature emphasises the importance of multi-agency input to self-neglect. Gunstone (2003), Day *et al.* (2012) and Lauder *et al.* (2005a) report that workers find it important to be able to draw on each other's complementary expertise and value perspectives on this complex issue, and to be able to share tasks and responsibilities. Yet Lauder *et al.* (2005a), in the only study to interview workers from housing, environmental health, health care and social work together, pointed out that workers needed a much clearer understanding of each other's roles in order to facilitate multi-agency working.

There has been discussion of Multi-Agency Hoarding Teams (MAHTs) in the USA as a way of facilitating multidisciplinary approaches to hoarding. Evidence for the effectiveness of MAHTs is inconclusive due to a lack of data and the high refusal rate of clients to engage with the service (Chapin *et al.*, 2010; Koenig *et al.*, 2013). Obstacles

to effective team involvement with hoarding come from lack of funding, lack of time, and a frequent lack of flexibility in agency responses (Koenig *et al.*, 2013). However, they are proposed as a less resource-intensive approach than individual cognitive therapies. Firm comparison data to confirm this claim are not presented.

### **Summary: workforce development needs for self-neglect**

The evidence base did not directly address workforce development needs. However, some limited data are reported on experiences of working with self-neglect. These are mostly qualitative studies based on interviews with workers and, to a lesser extent, with people who self-neglect. There is a pressing need for outcome studies to provide further data on 'what works' with self-neglect. In the interim, however, practice experience across a number of studies from the UK and elsewhere points to four major factors in effective working:

- knowledge of self-neglect and of the legal framework surrounding it
- assessment skills
- relationship-building skills and a client-centred approach
- effective multidisciplinary working.

These findings resonate with much of what was said in the interviews carried out for this study.

There are limitations to the literature considered in this review, beyond the obvious methodological concerns about the strength of evidence. One of the most notable is that the studies identified are overwhelmingly focused on social workers and their colleagues in other sectors such as health. They say little about the perspectives of support workers, advocates or carers. Another significant issue is that, since these studies did not focus particularly on workforce development, they say little about how the perceived priority areas they identify should be addressed. Also, there is little discussion about the agency context and how organisational systems may affect workforce learning and practice. These are themes that were picked up during the interviews carried out for this study.

#### **3.1.4 What is the available evidence on the costs of unmet need in self-neglect?**

Given the lack of studies on prevalence and need, it is unsurprising that no systematic work appears to have been done on the costs of self-neglect in the UK. Any mention of costs that exists in the literature is largely anecdotal (e.g., Slatter, 2007), and hence unlikely to be representative. Exceptions (e.g., Franzini and Dyer, 2008; McGuire *et al.*,

2013) are from the USA and thus unlikely to correspond to the costs of equivalent cases within the UK.

### **Summary: costs of unmet needs in self-neglect**

No literature providing robust calculations of the costs of self-neglect in the UK was located.

## **3.2 Evidence from serious case reviews and other inquiries**

### **3.2.1 Serious case reviews**

There is no requirement on Local Safeguarding Adults Boards to publish serious case reviews. The search found references in annual reports of two local authorities to serious case reviews where self-neglect was a feature but neither report has been placed in the public domain. One of the annual reports did comment that a conclusion had been the need to develop a self-neglect policy and guidance where individuals may not wish to accept support and where their ability to make decisions may vary over time. In addition, two Boards referred in annual reports to having commissioned and completed serious case reviews but provided no details. Nonetheless, 11 published serious case reviews (or their executive summaries) were located in which self-neglect is a feature, and details of these follow.

#### **3.2.1.1 Dudley (1)**

The case of AC (Dudley SVAB, 2010a) involves a man (aged 73) discharged from a hospital emergency department at his own request in the early hours, having persistently refused assessment and treatment. Security services staff left him at a nearby bus shelter where he was subsequently found dead. One noted feature of this case was the level of self-neglect by AC in relation to personal care, including neglect of his home and health, and alcohol misuse.

The executive summary contains a number of recommendations, including:

- the development of a multi-agency procedure and good practice guidance on self-neglect, mental capacity and best interest decision-making
- the provision of an awareness raising training programme to disseminate the key points in the new procedure and guidance

- that the Safeguarding Vulnerable Adult Board seeks reassurance from all agencies that:
  - gaps in training and development needs of staff relating to vulnerable adults will be identified and addressed
  - procedures are developed to manage and collate information when vulnerable adults are referred repeatedly for assistance, advice or assessment
  - health services monitor the needs of vulnerable people and their (non) attendance at appointments.

### **3.2.1.2 Dudley (2)**

The case of BD (Dudley SVAB, 2010b) involves a man (aged 39) with a history of anti-social behaviour, who was well-known to health professionals, and had alcohol dependency problems. He was frequently offered help that, equally frequently, he refused. However, agencies failed to recognise his degree of vulnerability and missed opportunities to intervene and support him in relation to his self-destructive lifestyle. Despite so much time spent on him by individual agencies, the multi-agency network failed, until after his death, to understand the full degree of his usage of health, social care, emergency and probation services. Agencies saw his constant and inappropriate use of emergency and health services as a nuisance and time wasting rather than what the frequency of the demands might signify.

The absence of a clear disability or diagnosable condition created significant problems of ownership between agencies, with advice to referrers to seek help elsewhere rather than taking responsibility for finding a solution. Some records of agency involvement were missing. Agencies did not appreciate that attacks against his property might have been motivated by racism or his perceived disability.

The report recommends:

- improvements in record keeping, especially chronologies of agency involvement and working together to maintain a co-ordinated record of involvement so that the full extent of problems and needs can be identified and responded to
- recording the involvement of safeguarding team staff on computerised records so that interrogation of the database by other social care teams or enquiries from other agencies can reveal concerns and how they are being managed
- sharing records so that agencies appreciate the totality of the organisational jigsaw in a case

- developing policies regarding high and repeat usage of services
- agreeing procedures about managerial oversight of complex cases and lead responsibility within and across agencies so that the approach remains co-ordinated and planned assessments and actions take place
- implementing minimum levels of training to ensure that staff recognise who is, or might be, vulnerable and know how to respond appropriately
- ensuring greater staff awareness of harassment and hate crime, and of appropriate responses
- promoting the importance of assessments that identify predisposing issues behind the presenting behaviour.

### **3.2.1.3 Nottinghamshire**

This case (Nottinghamshire SAB, 2010) involves a physically disabled woman living independently and aged 40 at the time of her death. The review acknowledges that it can prove difficult for agencies to detect if someone is underplaying their risks or avoiding service contact unless this results in harm, the more so when services are not designed to encourage people to share their fears. Nonetheless, there is a need to find opportunities to discuss the behaviour and encourage the person to receive support. The report also notes that people with long-term conditions benefit from consistent support to develop and maintain effective coping behaviours, and that investment in such support can produce good health and well-being outcomes with consequent savings for high cost health and care services.

The report's recommendations are that:

- staff challenge any climate of optimism and become aware of past significant harmful events
- electronic records are shared for information sharing and staff awareness of each other's roles
- one professional should lead and co-ordinate information sharing and whole system meetings
- risk assessment guidance and tools capture historical information of past harm, encourage reflection on current risks and protective factors, develop risk management plans and promote multi-disciplinary assessment and discussion
- supervision policies and management oversight of practice should be reviewed to ensure that workers are regularly supported and challenged. This includes ensuring their decision-making is focused on enabling service users to have maximum control of their treatment and support, that evidence of consideration of

capacity and risk is always recorded, that optimism is challenged where it is not supported by evidence, and that key decisions are recorded

- training and workshops should be held with professionals and with users and carers to share concerns, information about responsibilities, and good practice with adults who have capacity.

#### **3.2.1.4 Sheffield**

Ann, a former nurse and single parent, was in her mid-40s when she died as a result of pyelonephritis, urine infection and kidney stones (Sheffield Adults Safeguarding Partnership Board, 2009). She had been a wheelchair user for many years, with limited mobility and a range of more acute health concerns: muscular spasms, physical impairments and intermittent speech loss.

She was well known to health and social care professionals; over seven years there were over 900 interventions designed to assist her, and to support her in caring for her child (although her child was eventually taken into care). However, she persistently refused to engage with service personnel, either not allowing them access to her home or refusing to allow them to attend to health routines, personal hygiene and living circumstances unless under her exceptionally stringent conditions.

The working conditions in her home made professional practice extremely difficult and she gradually exhausted people's ability to engage with her. Capacity assessments concluded that she did have mental capacity, though it appears none were undertaken during the final months of her deterioration prior to her death. At the end of her life Ann lived in darkness, lying in her bodily fluids. Before she died she sent an email naming 20 practitioners she held responsible.

The serious case review recommends that:

- staff should be provided with support, including individual and peer supervision, and opportunities to debrief after interventions
- a senior manager should be allocated to lead real-time management of risk
- regular checks should be made of a service user's decision-making abilities as well as of their mental capacity when regularly refusing support
- information sharing procedures should be reviewed.

### **3.2.1.5 Blackburn with Darwen**

Blackburn with Darwen Local Safeguarding Adults Board (2011) conducted a serious case review on Joan, aged around 80, whose death was aggravated by self-neglect. Periodically she refused services and support. She did sometimes buy informal services, including meals, by telephone, and sometimes accepted laundry and shopping services, District Nurse support, and minimal cleaning, but not personal care. When in hospital, she occasionally refused treatment, including food and drink. Capacity assessments were not done and there was no evidence of use of research. Staff did not escalate their concerns to senior managers and no multi-agency case or risk management reviews were held. Staff worked hard to ensure care was sensitive and appropriate, despite her resistance, and accepted her decisions. However, they operated without agreed strategies to engage her and the reasons for her chosen lifestyle were not explored with her.

The report recommends:

- that policies are reviewed to ensure that cases of self-neglect are considered in safeguarding
- that an escalation policy is developed
- training and awareness raising on self-neglect alongside regular supervision to enable staff to remain resilient and to protect themselves and their organisations
- involvement of managers to contain high levels of anxiety and share the risks, and to ensure that good records are kept, that risk assessments are thorough and that practice is assertive.

### 3.2.1.6 Cornwall

JK was 76 years old when she died (Cornwall & Isles of Scilly Safeguarding Adults Board, 2009). She lived with her three dogs in rented accommodation. She was reluctant to leave her home and in the period leading up to her death was reported as spending most of the day on her bed with her dogs. JK was described as 'reclusive', but made contact with a range of services as she felt she needed them. Two 'core' assessments concluded that JK was able to manage her personal and domestic needs. JK's niece and nephew both expressed concern about her situation. People were unsure about her vulnerability and ability to manage. Her living conditions were unhygienic and unsafe, including dog faeces within the property, and she was not looking after herself adequately. Periodically, JK reported that she was being harassed, having money and medication stolen by people entering her home. JK was clear about not wishing to leave her home or change her situation. Everyone appeared to have attempted to persuade her to accept some help, which was consistently and coherently refused. All involved felt that JK had capacity to make these decisions. In the week before JK's death her health deteriorated rapidly but she refused hospital admission.

The report recommends:

- that staff should have the training to complete assessments that focus on the service user's perspective rather than available services and also address reluctance to engage
- that recording systems should allow a clear view of emerging patterns
- multi-agency assessments and meetings, with discussion of needs and risks, shared care plans and a nominated key worker
- that policies should clarify when cases of self-neglect become a safeguarding concern and should direct staff to identify levels of risk
- that reviews should be held when a service user's refusal of support leads to concerns
- that advice and guidance should be available to support staff to work in self-neglect cases; with training offered about effective approaches to work with people who refuse services.

### 3.2.1.7 **Surrey**

This case (Surrey Safeguarding Adults Board, no date) involved an 81 year old woman known to adult social care and mental health services. Both before and after her husband's death, she was offered services to address physical disabilities and dementia. Initially she accepted care worker support and a day centre, but subsequently declined. The serious case review found no evidence of risk assessments, capacity assessments and carer assessments when these would have been appropriate.

Refusals to accept services on several occasions did not prompt engagement with the individual and her daughters about her decisions, even when pressures on family carers were mounting and concerns about fire hazards were increasing. There was a lack of co-ordination between mental health services and the local authority. Care plans and assessments were not undertaken or reviewed jointly. Fire risks were not referred to the Fire and Rescue Service as required by policies. There was an absence of clarity about sharing information between agencies and no individual had overall responsibility for the case.

The review makes a number of recommendations, including:

- staff training to ensure that policies are known and applied
- audit of procedures so that agencies know how training is applied in practice
- training to advise staff when it is appropriate to intervene in an individual's best interests to keep them safe, when they do not have capacity
- robust supervision, review and management oversight of staff, especially in complex cases
- engagement with the individual service user and with family carers when services have been declined
- the development of an inter-agency protocol on information sharing
- the provision of written care plans for service users, family carers and staff, with a log book retained at the individual's home into which agency staff make entries
- multi-agency development, monitoring and review of care plans
- person-centred risk assessment and management, involving service users and carers, with training, supervision, management oversight and case audit to ensure that this approach is adopted
- the development of guidance with respect to people who decline services, including emphasis on risk assessment and management, mental capacity assessment and information sharing.

### **3.2.1.8 Southampton**

This serious case review (2012) concerned a man with learning and physical disabilities (aged 49) living in supported accommodation. He died of complications arising from dehydration, colitis and epilepsy.

Several factors were identified as contributing to deterioration in his quality of life over the preceding year. There had been a reduction in the one to one support allocated to him and he did not receive all the hours that he had been assessed as needing. Staff in the supported accommodation service were inexperienced and also unclear about their role. They were not assertive when he declined help; they did not question his decisions and had not been trained in how to do this. The accommodation environment had been allowed to deteriorate, with the result that outsiders gained entry and behaved anti-socially. A poor level of hygiene and cleanliness in his flat was allowed to persist.

There was poor communication between health and support staff, which resulted in a lack of awareness of his condition and specifically of how unwell he was becoming. When a safeguarding strategy meeting was held, his real needs were not addressed.

The review recommends that:

- strategy meetings should assess and review the needs of all vulnerable adults in a setting, including how they might interact
- meetings should confirm that care plans reflect the needs identified
- records should be checked routinely
- spot checks of the environment should be conducted and the support provided should be monitored
- written assessments should be compiled after visits; advice given during, and outcomes of visits should be recorded
- concerns about care being given should be raised immediately
- staff should be trained in techniques to assist them when service users disengage or refuse support
- relatives should be informed when the service user is unwell
- capacity assessments should be considered when service users disengage or refuse support.

### **3.2.1.9 Birmingham**

This serious case review (2010) concerns a learning disabled man (aged 34) with mental health needs, living at home with his parents and siblings. He was not known to adult social care before his death but care and treatment were periodically provided by primary care, community nursing and mental health services.

At times he, or his mother on his behalf, refused medical and nursing treatment, at home and admission to hospital, with the result that he developed serious complications in his legs (including gangrene) and experienced reduced mobility. His mother had a phobia of hospitals and this influenced him to refuse admission when offered. It was assumed that he had capacity when making this decision. His mother was not offered a carer's assessment.

Concerns about his self-neglect were noted by health care staff but not referred to adult social care or to adult safeguarding. Eventually he agreed to hospital admission where a 'best interests' assessment led to treatment (double amputation) in an attempt to save his life. This was unsuccessful.

The review recommends:

- improvements to multi-agency working and the development of procedures to follow-up a service user's failure to keep appointments
- the development of guidance and the provision of training about service refusal, to ensure that assessments and case conferences are triggered and service users advised about the implications of treatment refusals
- agreement on protocols for information sharing
- training to provide legal knowledge and skill development regarding mental capacity assessment, adult safeguarding procedures, and assessment of the needs of carers.

### 3.2.1.10 *Warwickshire*

The murder of Gemma Hayter (aged 27) prompted this review (Warwickshire Safeguarding Adults Partnership, 2011), which found evidence of self-neglect alongside a chaotic lifestyle, inability to manage money and tenancies, intermittent engagement with support workers, and vulnerability to abuse and crime. Her behaviour towards professional support was characterised by refusal of assessment and failure to engage, although she did sometimes indicate a wish to change her lifestyle. No-one appeared to have explored her vulnerability with her and the report comments that a person's apparent choice should not be used as a rationale to ignore a professional duty of care.

Gemma's desire to protect her independence resulted in her covering up abuse she had experienced, but agencies missed opportunities to engage with her and assess risk due to self-neglect and lack of daily living skills. Conflicting diagnoses about whether she had a learning disability, conduct disorder or autistic spectrum disorder created barriers to accessing assessments and support.

No single agency had a full picture of her life. Risk assessments were not done to underpin decision-making, for example about case closure. Mental capacity assessments were not completed. Gemma was assumed to have capacity and a right to choose risky decisions and her lifestyle. The multi-agency system did not respond to a large number of low-level triggers. Agencies addressed the case within the terms of their own remit, sometimes misunderstanding the legal rules, for example concerning assessment for social care. There was no full overview of effective multi-disciplinary working, with no systems for discussion of concerns about vulnerable adults without their consent so that information is shared and assessments are accurate.

The serious case review recommends:

- that procedures and practice guidance are developed for:
  - protecting people at risk of abuse
  - management oversight of complex cases
  - case recording
  - risk assessments, especially where cases do not meet thresholds for specialist services or are considered for closure
  - escalating concerns and requesting multi-agency meetings
- training for housing officers and other staff on adult safeguarding and on the legal rules relating to assessment duties.

### 3.2.1.11 *Worcestershire*

This case (Worcestershire Safeguarding Adults Board, 2010) involved a 58 year old man with mental and physical health problems, living in a housing association bungalow, receiving special support from the landlord to help maintain his property. His body was found at home by police.

He had been known to mental health services for depression, anxiety and behavioural problems and to his general practitioner for physical ill-health and the condition of his home. His parents had sometimes hidden his escalating problems, which meant that opportunities for a full assessment of his lifestyle and his ability to care for himself were missed. He had a history of misusing prescribed medication and over-the-counter drugs.

More latterly adult protection services had been involved because of concerns about his mother's vulnerability and the impact of his behaviour on her. He was assumed to have mental capacity. Despite some good practice there was a lack of multi-agency working and holistic assessment and intervention, and insufficient professional curiosity about problematic engagement with services. He was not seen as vulnerable through self-neglect despite behaviour problems, poor physical health and out-patient non-attendance. Evidence of self-neglect was not fully considered and escalating problems did not prompt review. His mother's needs might have diverted attention from his own. Notions of confidentiality impeded communication with his family.

The report recommended:

- that guidance be reviewed and cross-referenced to facilitate family involvement and information sharing in order to balance individual privacy with appropriate exchange
- the role of family members should be clearly recorded and consideration given to their proactive involvement
- that recording be improved
- that supervision be reviewed to assist in the identification of need for a multi-agency approach where there is an adult at risk
- multi-agency guidance on problematic prescribing and medication misuse, including the involvement of pharmacists
- training on self-neglect.

### **3.2.1.12 Other serious case reviews**

One summary was of a case in which self-neglect was not apparent in the case description, but where the recommendations included the need for attention to self-neglect.

#### **Bath and North-East Somerset**

Ms A (deceased) (BNES, 2011), whose exact age is not given, had received much community support from mental health and learning disability services prior to moving into a residential setting where her mother was also placed. She was subsequently transferred into a nursing home where her health deteriorated and concerns were raised about possible neglect

The summary report contains several recommendations, namely that:

- multi-agency guidance and protocols for practitioners be reviewed in order to improve the definitions and thresholds for neglect and safeguarding adult actions, and to strengthen arrangements for case management and coordination
- multi-agency training be reviewed, including that for senior managers and for General Practitioners, to support improvement in practice for key staff in safeguarding thresholds, neglect, self-neglect and cases of serious illness and palliative care to ensure high standards of professional assessment and practice.

Two further cases were identified that investigated situations falling within the definition of self-neglect, but where the serious case review summaries do not frame the circumstances in this way.

#### **Gloucestershire**

A serious case review was conducted into the case of an older person who died in a fire (Gloucestershire Safeguarding Adults Board, 2012). All agencies had been aware of his living conditions, his vulnerability and the risk of fire, following disconnection of his electricity, but no agency took responsibility for taking preventive or protective action. He would not pay for the necessary electricity repairs but no referral was made to the Fire Service after his disconnection and his family were not advised of the dangers to which he was subjecting himself. He was deemed to have capacity and adult social care closed his case.

The report recommends that:

- staff must be rigorous and inclusive of all those involved in the care and support of older people, including family members
- practice guidance should be available for staff working with vulnerable adults who have capacity but who put themselves at risk of harm
- the development of procedures and practice guidance on risk recognition and management
- training for staff to be able to identify and initiate appropriate protective action with respect to risk, including fire risks.

## **Torbay**

A Torbay Safeguarding Adults Board case relates to a young woman (aged 30) who was dependent on drugs and alcohol, was the victim of serious physical violence, was extremely vulnerable, had life-limiting liver disease and multiple hospital admissions and self-discharges.

At times adult safeguarding procedures were invoked, including strategy meetings, and there was considerable knowledge within agencies of her health and social care needs. However, the purpose of interventions and desired outcomes were not effectively shared across agencies. Her non-compliance and her lifestyle exacerbated her ill-health and her vulnerability but no-one made persistent attempts to form an influential relationship with her. Rather, her repeated denial and rejection of help proved deeply frustrating for staff who turned their attention elsewhere and limited their involvement to reactive rather than preventive and proactive attempts at change.

Staff had insufficient understanding of addiction and dependence on alcohol and drugs, and believed that her choice overrode other considerations. Staff failed to consider whether her behaviour and lifestyle was symptomatic of a serious illness. There were missed opportunities to assess her needs and to make adult safeguarding alerts. The review recognises that the exercise of adult self-determination, involving risk-taking, makes safeguarding work difficult but suggests that routine capacity assessments might have indicated whether she did in fact have capacity at all times.

The review recommends that:

- staff must be aware of adult safeguarding policies
- complex cases, involving non-compliance, should be discussed in case conferences, for example before a vulnerable adult is discharged from hospital

- staff awareness of alcohol and drug misuse should be raised
- recording of contact with vulnerable adults should be standardised
- guidance should be produced on when and how to conduct mental capacity assessments
- all staff with highly complex cases must have access to support and case oversight.

### **3.2.2 Ombudsman investigations**

There have been several ombudsman investigations into cases that feature adults who self-neglect. In a case involving Worcestershire County Council (2011, case 09013172), the ombudsman concluded that there had been maladministration because home care staff had left the house and service user dirty. The person's hygiene, dress and food intake had not been adequately monitored, and there had been no review of the care package and plan. The result was that the condition of the house had been allowed to deteriorate significantly. There did not appear to have been a comprehensive strategy to manage known risks posed by the service user's lack of capacity, for example a tendency to overdress in hot weather.

Another case involved an NHS trust and local authority providing medical and psychiatric interventions, together with cleaners and support workers (PHSO, 2011). At times the individual was living in a filthy and insanitary state despite this support, with periodic hospitalisation for malnutrition and dehydration. He was known to self-harm, to have mental health needs and difficult personal relationships, to experience social isolation, and to be neglectful of his dietary needs. There were risks regarding his level of understanding and insight. He was difficult to engage but did allow his house to be cleaned when dirty.

This investigation noted that staff involved with him wanted to respect his autonomy and independence. However, the risk assessment and plan clearly identified risks of self-neglect that, according to the plan, should have been escalated when they were materialising. However, this did not happen. Equally, the Community Psychiatric Nurse's (CPN) workload was identified as a problem, coupled with guidance through supervision not being robust enough to ensure that appropriate action was taken by the CPN. The inquiry concluded that there had been maladministration. The reasons were that the care plan had not been fully implemented or managed, risk management had been inadequate, especially when there were developing signs of risk, and there had been insufficient contact and intervention, especially when the service user's living conditions were deteriorating and he was neglecting his personal health. There did not appear to have been appropriate assessment or discussion of capacity.

### 3.2.3 'Hidden in Plain Sight'

A report into disability hate crime, and the multi-agency response to it (EHRC, 2011), includes the case of Brent Martin, an adult assessed as at risk of self-harm, self-neglect, exploitation and violence. He lacked life skills to recognise harm and danger. He sometimes failed to co-operate with prescribed medication. The report recommends from this case training for all public facing staff on people at risk of harm and on hate crime. It stresses that staff must be competent in recognising risk and coercion.

#### **Summary: key themes for workforce development from serious case reviews and investigations**

Reviewing the key messages emanating from the serious case reviews, with particular emphasis on workforce development, a number of commonalities emerge, namely:

- many of the serious case reviews recommend that the reports are used for training and awareness raising purposes
- advice and guidance should be issued so that staff know how to work with cases of self-neglect, when to escalate concerns about risk, and when to include such cases within an adult safeguarding framework
- there should be senior management oversight of such cases
- a multi-agency approach is required, that includes ongoing assessment and risk management
- training should be provided that draws on the latest research on working with cases of self-neglect and that enhances the skill set of those required to assess capacity
- the importance of assessing capacity is stressed, along with training to ensure competence in doing so, especially when service users disengage or refuse to accept supportive interventions
- the importance of understanding the available legal rules is emphasised, for example regarding the assessment of carers. Equally it is important to help practitioners develop skills in assertive and questioning outreach to service users and their carers. This could include discussion of risk, exploration of service users' apparent lifestyle choices and the possible implications of their decisions
- supervision should be robust in terms of challenging optimism, scrutinising work done and following through decisions made at conferences, with key decisions noted.

These recommendations accord with conclusions reached in a general review of

serious case reviews (Bestjan, 2012). She highlights staff training to ensure competence in dealing with complex cases and challenging behaviours, including awareness of specific conditions, mental capacity and risk assessment. There is a need for management oversight of staffing levels and for joint working. Staff must also appreciate that mental capacity is not static and that it is especially important when support has been declined, when there are changes in patterns of engagement and when an individual's health and well-being is deteriorating.

Competence in risk assessment, capacity assessment and care planning is vital, but she found that some capacity judgements had been made without formal assessments. She notes that serious case reviews have found that disengagement did not always trigger re-assessment of needs and risk, or a re-evaluation of risk, as a prelude to considering the need for more urgent action.

She recommends the development of an inter-agency protocol on self-neglect something that not all interviewees and focus group participants had within their employing agency or multi-agency network. She further recommends that guidance is developed on working with people with capacity, who make unwise decisions, and on exploring with them issues underlying their decision-making.

### **3.3 Findings from interviews and focus groups**

The following section reports on the findings from the interviews and focus groups undertaken with staff in the five participating authorities. The analysis groups the findings in the following way:

- the volume of self-neglect work undertaken by the agencies involved
- the nature of self-neglect work being carried out
- perceived challenges of self-neglect practice
- workforce development needs for self-neglect practice
- perceived challenges of workforce development for self-neglect practice
- new initiatives reported in workforce development for self-neglect practice
- the costs and benefits of self-neglect practice and of workforce development initiatives
- perceptions of the role of Skills for Care.

### 3.3.1 Volume of self-neglect work undertaken by the agencies involved

None of the agencies from the five participating authorities was able to give any evidenced quantification of the volume of self-neglect work being carried out. All offered good data on safeguarding. However, they recognised that their statistics, in line with national expectations, would show only the categories of abuse and neglect involving third parties. Even where such situations involved self-neglect, this would not reliably be captured by the data. One authority signalled an intention to add self-neglect as a category within safeguarding statistics. Equally it was recognised that the variability in referral pathways and thresholds, and indeed the fact that self-neglect work may be conducted by providers independently of any case-holding by adult social care, would mean self-neglect work could not currently be accurately quantified. The lack of shared definition only compounded this difficulty: as one participant said, *“if you’re going to count something, you have to be able to define it first”*.

Against this backdrop, some participants were able to offer guesstimates about how much self-neglect work was being carried out as a proportion of all work. Here the figures varied hugely:

- *“My guesstimate would be between 10% and 20% of the hostel population, with perhaps the 10% representing those with the most acute needs”*.
- *“Between one and two cases at any one time”*.
- *“A caseload of 117 cases, of which 23 have an element of self-neglect”*.
- *“Maybe three or four people out of 90”*.
- *“Maybe 5% of adult social care cases”*.
- *“Perhaps four to five cases per week, but some teams one or two per year”*.
- *“Maybe 20% of my caseload”*.
- *“A caseload of homeless people, all of whom show self-neglect”*.
- *“Of 26 cases, 50% are self-neglecting”*.

Among participants, there was a perception too that self-neglect work was increasing, possibly as a result of changing demographics, or spill-over from greater public awareness about safeguarding: *“either it’s increasing, or practitioners are more anxious”*. Sometimes the trigger had been a serious case review that had stimulated a change of practice:

*“we concluded we needed to give these cases greater scrutiny rather than just doing an initial assessment of capacity and walking away”*.

Equally, it was recognised that people who self-neglect may not make it onto caseloads:

*“sometimes people we signpost elsewhere because they have only moderate need will have self-neglect issues”.*

Participants also made the point that where self-neglect is dealt with successfully, most probably on a daily basis, it does not trigger the level of concern that causes it to be labelled as such. The proportion of self-neglect work was thought to vary between teams, with services such as mental health, homelessness and substance misuse having a much higher concentration. Even if the proportion was in some cases small, the volume of work represented was disproportionately high, and the impact on how effectively people could progress through pathways was significant:

*“all are cases of self-neglect, usually with multiple diagnoses and social pathology, where self-neglect is preventing them from accessing the services that anyone who wasn't self-neglecting would be using”.*

### **Summary: volume of self-neglect work**

There were no data on the overall volume of self-neglect work being carried out. Contributing factors to this situation include variability in referral pathways and thresholds, the range of agencies involved, the lack of a shared definition and the lack of any national requirement to count cases. Guesstimating the volume of self-neglect work as a proportion of all work brought widely varying results. These were dependent upon the nature of the agency giving the guesstimate, with services such as mental health, homelessness and substance misuse having a much higher concentration. There was, however, a widely-held perception that such work was increasing.

### **3.3.2 The nature of self-neglect work being carried out**

#### **3.3.2.1 The scope of self-neglect practice**

Participants gave descriptive accounts of the self-neglect practice being undertaken, which clearly varied according to the differing functions of the agencies involved. For voluntary organisations, clients could present with a range of different manifestations: hoarding and poor living conditions, which included insanitary conditions, extreme dirt and rotten foodstuff. These were associated with a range of underlying features such as mental health needs, dual diagnosis, learning disabilities, anxiety, depression, bereavement or substance misuse. For clients accommodated elsewhere, concerns were often identified by chance:

*“when contractors call to carry out gas inspections or general repairs...they are not generally known to any of the statutory services”.*

Services could include practical, short-term interventions:

*“We provide showers, laundry and health care facilities; we monitor and seek to improve people’s personal hygiene, use of meal facilities and engagement with support services”.*

On occasion such provision is the only service that clients will engage with. Housing providers referred to providing one to one support to residents with a focus on cleaning. They used agreed behaviour contracts and warnings for infringement, and facilitated interventions from specialist services such as mental health or behavioural support. In extreme cases accommodation had continued to be provided when health care for a terminal condition had been refused.

Examples were given of how keyworkers could gradually gain the trust of clients, and through that trust begin to intervene in hoarding behaviour. They could then assist and support a sorting and recycling process, backed up, if necessary, by health and safety warnings to reinforce the requirement. It was emphasised that there was no ‘intervention formula’ to be applied, and that the approach taken was individualised to each and every client.

Examples were also given of work to support people with specific life transitions, such as entry to employment. The focus would be upon self-neglectful behaviours such as body odour, hygiene, clothing and self-presentation that may have developed during periods of mental ill-health, isolation or institutionalisation, but would create barriers to successful employment. Here, the approach would both provide practical guidance and encourage an external focus in the individual, delivered through the medium of a relationship prioritising reliability and trust.

### **3.3.2.2 Referral pathways**

More broadly within adult social care, referrals could also be received from a wide range of sources, including ambulance crew, fire services, police, concerned neighbours, hospitals, occupational therapists, day services, and meals on wheels.

*“The common factor is that referral is never from the client; they think they can manage, or they’re too ashamed to ask for help.”*

Referral was not uncommonly triggered by another agency's solution to the problem, as when eviction takes place. Older people predominated. Examples were given of work to contain extreme risks, whilst respecting the wishes of the individual concerned. One included keeping a room available in a residential care setting for an individual whose core preference was to remain on the street. They could access the room when they chose to do so and on this basis health and care services could be provided. Another example was of a relationship that was built by the worker taking part, alongside the client, in activities the client had enjoyed in the past, prior to bereavement and depression.

### **3.3.2.3 Workforce groups involved**

The range of workforce groups involved in self-neglect work was wide. It included practitioners at very different levels of qualification and experience, working in adult social care, for people with mental health problems or a learning disability or older people, homelessness and substance misuse teams. They also worked in provider services, including residential, domiciliary and floating support, environmental health and housing, and in various health services. Other groups, such as library staff, refuse collectors and street sweepers, could be crucially involved in identification and referral. Up to 90% may not be employed by the council.

*“Some regard self-neglect as a rewarding challenge, whereas others struggle with those challenges; professional background and experience, individual manager attitudes, the role and purpose of the specific service – all make a difference”.*

No authority made any claim to have devised a systematised way of allocating different types of self-neglect work to various workforce groups:

*“We don't really have a clear view on how we prioritise and categorise that group of people. It would be dependent on the manager of the service as to how they allocate a piece of work – it might go to an unqualified worker if the task is non-specific support; or a case might be closed to the qualified worker but the support worker might remain involved”.*

Some respondents recognised that this was specialist work that would ordinarily be allocated to experienced practitioners.

### Summary: the nature of self-neglect work being carried out

The nature of the work varied according to the differing functions of the agencies involved. There was no formula for intervention, and the approaches taken were much individualised. Referral pathways to adult social care involved a wide range of agencies, but many people were receiving support outside of any statutory adult social care framework. Services might focus on practical, short-term interventions such as help with cleaning, hygiene or healthcare, or work to support life transitions such as a return to employment. Threat to tenancy, or the use of environmental health legislation, was often a lever to secure a degree of engagement. However, building a relationship of trust was seen as a more powerful vehicle to understanding the individual's unique perspective, and finding creative ways to provide support and minimise risk. Similarly, a diverse range of workforce groups was involved, with practitioners at differing levels of qualification and experience. No authority had devised a systematised way of allocating different types of self-neglect work to various workforce groups.

#### 3.3.3 The perceived challenges of self-neglect practice

Although the challenges of self-neglect practice were not the key focus of the study, it proved necessary for many of the participants to share and explore their experience in order to move then to consideration of workforce development needs.

Perhaps one of the most deep-seated challenges, affecting individual practice and organisational service systems alike, was that of defining self-neglect. There were debates about whether it included hoarding, suicidal behaviour, street drinking, homelessness, substance misuse, and a range of ways in which services for risk minimisation could be refused. Associated with this was the challenge of finding an organisational location for it. Even in the small number of authorities involved in giving responses in this small study, there were key differences:

*"We're clear self-neglect is not safeguarding".*

*"We're not sure safeguarding is the right framework to use, though it does provide a framework in the absence of any other".*

*"We deal with it through safeguarding now".*

The remaining challenges recounted fell into two broad categories: those related to self-neglect *itself*, and those related to the organisational and service environment.

### Summary: the perceived challenges of self-neglect practice

The most deep-seated challenge affecting individual practice and organisational or service systems alike, was that of defining self-neglect, and the associated challenge of finding an organisational home for it. It could be perceived as everybody's or nobody's business. More broadly, challenges clustered into two groups:

- challenges related to self-neglect *itself*
- challenges related to the organisational and service environments in which self-neglect work takes place.

#### 3.3.3.1 Challenges related to self-neglect itself

##### a. The complexity of self-neglect

Practitioners experienced the sheer complexity of self-neglect as a major challenge. Many felt they lacked knowledge about its causes and development. Although they understood the likelihood of a complex interplay of factors, the task of matching intervention to cause was made more challenging as a result of this complexity:

*“the underlying mental health issues are still there, even if we send people in to clean”;*  
*“it's not enough just to clean somewhere; it's more fundamental than that – how can we understand what's beneath and help with it?”*

They experienced certain manifestations of self-neglect as particularly challenging; for example, awareness of the fire risks from hoarding was high, as was recognition of risks from lifestyles that threaten skin integrity, given the rapid likely decline in health.

##### b. Contrasting agency perspectives

There was recognition of variations between agencies in whether self-neglect would trigger concern, and of the impact of the social environment, both in bringing self-neglect to attention and in determining necessary responses:

*“In some cases you wouldn't intervene if they lived in the middle of a field with no-one else around them to be worried or annoyed”.*

This question of thresholds emerged also in discussions about interagency working. There was recognition that some services, e.g. mental health, might have higher thresholds for concern, and therefore fewer triggers for intervention, than adult social care. It was also recognised that that others, such as housing, police or ambulance

crew, may have lower thresholds that resulted in pressure on adult social care to 'do something'.

### **c. The challenges of assessment**

There was widespread awareness among participants that the complexity of self-neglect, and the challenge of engaging service users, made assessment difficult. However, it was recognised that often the organisational context posed the greatest challenge. This is expanded further in the next section below. Self-neglect was seen as requiring an approach that prioritised in-depth personal understanding of an individual's circumstances and personhood: "*you have to really get to know someone before you know what self-neglect is about*". This involved a delicate balance between hands-on and hands-off approaches, carefully calibrated to the individual:

*"people who self-neglect don't want lots of people doing things for them, but support to get by...we're mindful that if we push people to do things they don't want to do we will get nowhere at all because they'll shut the door."*

### **d. Balancing competing principles**

Many practitioners, in all parts of the sector, were acutely aware of the tensions between respect for autonomy on the one hand and a duty of care on the other:

*"There are conflicting views between a client's right to make choices and managing the risk of harm or death."*

The question "*what right do we have to intervene in the unwise choices of someone with capacity?*" was commonly raised. Personalisation came across as a strong driver for a position of respect for autonomy, but concerns still arose for practitioners and their employers in circumstances where user-defined outcomes challenged notions of human dignity. Practitioners were particularly mindful that they may be called upon to defend, against external criticism (from quarters such as the coroner), the decision not to intervene, nor to impose solutions that would be resisted by the client.

Even where the right to make autonomous decisions was fully recognised and endorsed, there was mention by some practitioners of a 'tipping point' beyond which tolerance could not go, although there was no explicit agreement about what that might be. Others found it challenging to live with the outcome of assessments that confirmed capacity to make lifestyle choices in which human dignity was seen as deeply compromised, although they recognised that this was an inevitable outcome of respect for capacitous autonomy. A significant challenge was the recognition that people who self-neglect may not exactly be exercising choice, but continuing an established familiar

pattern, and may not have all the information relevant to making a specific lifestyle decision: *“how do we enable people to make decisions if they don’t know what a better life looks like?”* The professional task here was construed as giving people ways of exploring alternatives without imposing those alternatives, presenting choices where people have never exercised positive choice before:

*“Respecting lifestyle choice isn’t the problem; it’s where people don’t think they’re worth anything different, or they don’t know what the options are.”*

But challenging or expressing curiosity about the decisions that people were making, when these exposed them to serious risk, was not an automatic part of practice.

#### **e. Mental capacity**

Mental capacity was commonly recognised as a key factor in assessment and a pivotal determinant of intervention options. Whilst most respondents had had some training on capacity, and some had experience of capacity assessment, depending on their job role, this remained a challenging area:

*“People are more comfortable now with the theory, but the assessment bit is where people remain uncomfortable, particularly where it’s borderline.”*

Fluctuating capacity was also experienced as a challenge. The point was made that capacity assessment in such circumstances was likely to require ongoing engagement over a period time before a true picture could emerge. Practitioners reported difficulty in securing specialist advice on cognitive deficit, as well as conflicting advice from colleagues in different services: *“sometimes the social worker and the doctor have come to different conclusions”*. Equally, capacity assessments from other professionals, in this case in the context of hospital discharge could be experienced as incomplete:

*“It’s just recorded that the person has capacity, not in relation to what, whereas we need to be more thorough and address every arena they’re going to have to function in.”*

There was evidence of concern about fault lines in capacity assessment, such as lack of ongoing capacity review, and a lack of focus on the ability to execute a decision: *“people can tell us they will do that, but we don’t test whether they can do it.”*

#### **f. Interventions for self-neglect**

Practitioners described themselves as often at a loss to know how to approach intervention. Many of the recognised forms of intervention targeting behaviour change – agreed behaviour contracts were given as an example – rely upon consensual

engagement from the service user. Some felt they lacked knowledge about who could and should be brought on board from within the interagency network, and what they could reasonably ask for or expect from other agencies. There was much discussion of the role of enforcement, and the extent to which this could be a lever for longer-term change. In the experience of most people, it could result in short-term improvement, and damage limitation, such as averting an eviction, but many expressed frustration and doubt at the extent to which it could address root causes. Equally, there were many examples of creative and imaginative practices that sought to maintain some contact, even through a third party, or to mitigate the most acute risks. It was clear that, despite the challenges of uncertainty, many practitioners devised thoughtful and reasoned interventions.

For many practitioners there was discomfort in settling for harm reduction strategies in intervention, and the achievement of a 'least bad' outcome, rather than the neat and tidy solutions that might be more comfortable. Thus, a further key challenge lay in identifying outcomes that are achievable in the context of behaviours that make complete resolution unlikely.

For some, the absence of suitable practical facilities was a barrier to effective intervention. An example might be to provide temporary accommodation, if it existed, following hospital discharge, to achieve a staged return home. This could enable unsustainable home conditions to be rectified.

#### **g. The legal framework**

Some respondents mentioned uncertainty about the legal framework. Views ranged from concern at there being "*no legislation*", to recognition that there existed a complex framework of legal rules about which agencies and professionals had no common understanding. Indeed, there was disquiet about the potential for inappropriate legal interventions, triggered by acute concern about unwise decisions that result in risk to life. Access to legal advice was generally available, although in some local authorities it could only be obtained following permission from senior managers.

#### **h. Effects on practitioners**

The impact of self-neglect work received some attention, with strong emphasis placed on the frustrations and anxieties of practice. In some cases this involved standing by, and watching deterioration on a daily basis. Yet others recognised they could become almost immune to the impact: "*it's insidious and cumulative; people can work for months and not realise how it's deteriorating.*" Pressure from families, communities and other services could "*make practitioners quite jumpy*", with fear and anxiety about outcomes intensified by the anxieties of others. In the face of the challenges of working in self-

neglect, it might have been anticipated that support structures too could be experienced as lacking, but this was not the case. There was discussion about the need for supervision and support (covered later in the section on workforce development needs) but the experiences of participants were generally positive and constructive.

#### **i. Training**

It was rare for respondents to have received training specific to self-neglect work, although some authorities had commissioned training on specific manifestations, such as hoarding, linked to input on obsessive compulsive disorders. In one authority a specialist behavioural support service had provided training and support to keyworkers, in order to resource their direct work with clients. This had been found to be a constructive and positive way in which to build capacity and confidence in the staff group. More common, however, was the process of staff drawing on training received on other topics, and transferring the learning into their approach to self-neglect. Some local authorities and partnership structures had developed policies and practice guidance, on self-neglect generally, or hoarding specifically, which practitioners reported helpful.

## Summary: challenges related to self-neglect

These included:

- self-neglect and its manifestations are complex and can pose very high risks. Reasons for self-neglect, and means of intervention, are likely to be contingent on a complex interplay of factors
- contrasting agency perspectives on thresholds that trigger concern
- the need for assessment to take account of the complexity of each individual's circumstances and the difficulties of engagement
- balancing competing imperatives, in particular the tensions between respect for autonomy and a duty of care, in the recognition that levels of tolerance for loss of human dignity may vary and autonomous choice may be compromised
- assessment of mental capacity, particularly fluctuating capacity, and the difference between decisional capacity and executive capacity<sup>3</sup>
- interventions for self-neglect when many recognised forms of intervention require consent from the service user, and where the use of enforcement was recognised as necessary on occasion, but unlikely to lead to long-term change
- legal frameworks about which practitioners were uncertain or uneasy
- effects on practitioners, including frustration and anxiety
- lack of training specific to self-neglect, requiring learning to be transferred from other topic-based training input.

### 3.3.3.2 Challenges related to the service culture

#### a. Eligibility for adult social care

There were perceived to be barriers to accessing adult social care for people who self-neglect. The existence of strict eligibility criteria for adult social care (DH, 2010) could have the effect of excluding people who self-neglect from accessing a service if they do not reach the thresholds for substantial or critical risk. Yet early intervention may well be called for to prevent entrenched patterns that eventually lead to critical-risk situations:

*“We do make referrals to adult social care if people have particular needs (that could engage a statutory response) but a lot of people don't meet the criteria, so it tends to be over to us in (voluntary agencies).”*

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<sup>3</sup> Decisional capacity refers to the capacity to make the decision. Executive capacity refers to the capacity to implement or carry out the decision.

Although there was some evidence of flexibility – *“on the whole social care are pretty good at applying a common sense approach”* – there was also evidence of ambivalence on the part of adult social care about whether self-neglect was a priority:

*“As soon as it’s not a safeguarding issue, then the involvement ends, rather than considering the duty to preserve life.”*

Conversely, some participants expressed discomfort at eligibility determining intervention. They argued that a duty of care exists, even where the threshold for eligibility for services is not reached.

Referral through making a safeguarding alert was seen as one alternative route by agencies outside adult social care: *“but it usually comes back as a level one, which is back to us to deal with, so we’re back at square one”*.

An absence of response from adult social care could mean that independent sector organisations take on work that is in excess of what might be expected:

*“We’re looking at support hours being quadrupled, quintupled, for clients for whom this is an issue; some of our services are putting in almost half a post to one client because of his self-neglect; we haven’t formally agreed that, it wasn’t commissioned, but that was what had to happen...because it’s the only way to prevent him from ending up on the street.”*

#### **b. The goal of independence**

People who self-neglect challenged the norms of a service culture that prioritises independence:

*“We have services that are set up to support people to do things for themselves; training, induction, workflow systems are all designed to this end.”*

This was particularly acute for independent providers, who may be commissioned to provide time-limited programmes, designed to achieve independence for the service user. People with self-neglectful behaviour would not necessarily progress through the programme within the commissioned timescale, and again the services commissioned were not those that will address the underlying problems:

*“What might work doesn’t fit with how we currently organise things ... they don’t fit within the pathway to independence.”*

The result was that services intended to be time-limited can grind to a halt because they are providing long-term support to maintain a status quo rather than facilitating change. An added frustration for practitioners here was that such interventions are almost always practical, yet they are provided in the recognition that they are not addressing the underlying problem:

*“Cleaning up isn't necessarily a positive intervention; it's often triggered as a last resort to prevent someone ending up on the street through breach of tenancy.” “We go in, do a clearance, it gets left; a year, two years later we have to go back in again.”*

Respondents who made these points reflected that there was perhaps a need to review how service commissioning could shift its focus to introduce clinical interventions, with a therapeutic aim, into the service mix from providers. This was thought to be particularly necessary where adult social care is unable to engage in an integrated approach, providing the psychosocial intervention, whilst third sector organisations proactively deliver practical support.

### **c. Workflows and care management**

A frustration for practitioners arose from the workflow patterns in which assessment and intervention takes place, a context that was perceived as prioritising care management rather than longer term involvement: *“you identify what's broken, fix it, move on to the next one”*. Self-neglect sat awkwardly within this:

*“We need a structure that allows a good analysis of the situation before you start thinking about what, why and how. We rush things too much, see the problem and want a solution. More time is needed with these cases, and this needs both an organisational and an individual practitioner space for such an approach.”*

In contrast, the ways in which workflows were structured usually meant that the case would be closed where service refusal (common in cases of self-neglect) is made with capacity. Many practitioners emphasised the importance of organisational systems that would allow them the flexibility to maintain an ongoing contact, to appear to be ‘doing nothing’ in terms of outcomes achievement, whilst taking time to gain an overall picture and build a relationship that could achieve change in the future.

*“To be able to help them you have to be able to stay with the case for a long time, but from our manager's point of view they want to close the case as soon as possible.”*

Equally, provider services were under time pressures that didn't fit with the self-neglect context:

*“No time allowance is made for waiting for the door to be opened; a completely different culture is needed, one that isn’t so time management focused”.*

Thus for many, practitioners and managers alike, self-neglect practice involved moving outside of organisational policy on workflow practices, and having the confidence to do that. Sometimes this appeared to be a decision taken by a worker alone; sometimes it was endorsed by the manager and the organisational culture.

#### **d. Inter-agency and inter-professional environment**

A further challenging feature of the service culture was the interagency and inter-professional environment in which self-neglect is located. Whilst many examples were given of positive collaboration between services, others reported a less integrated picture. Sometimes it was difficult to secure specialist assessments that took account of the particular capabilities of someone who is self-neglectful, with services retaining a focus solely upon their own perspective or priority. Hospital discharges made without warning were one example; another related to fire prevention:

*“We have had visits from the fire service to talk about fire risks, but the challenge of mitigating risk in the context of self-neglect doesn’t seem to be recognised.”*

Conversely, there was concern about perceived over-reaction to self-neglect, resulting in quick judgements being made without consultation – such as ambulance crew refusing to return someone to poor home circumstances – and about fundamentally different approaches to practice and priorities:

*“We’re always the ones saying hold on there, slow down, let’s have a think; others are more risk averse, want us to sort it out and get rid of the problem.”*

*“Housing have responsibility for all their tenants, and their interest is to solve the problem for all, whereas our focus is on that one person; we have quite robust conversations about this.”*

Negotiation between agencies was felt by some to take even more time than working with the individual client, *“because the structures can be immovable”* and there was a culture of it being nobody’s problem.

*“Services don’t get together soon enough and work together constructively; we create barriers for each other...it’s very hard to join it all up.” “Everybody’s got their own agenda and what often happens is that the person’s voice gets lost.”*

Thus, it could be very difficult to bring together a critical mass of the right people in the right place with the right frame of mind for shared discussion and problem solving.

### **Summary: challenges related to the service culture**

- Barriers on access to services through the operation of eligibility thresholds making it difficult to work preventively.
- A service culture that prioritises independence as a goal and operates care pathways that are not achievable in cases of self-neglect.
- Workflow patterns based on time-limited care management rather than longer-term involvement that would enable relationships to be built over time.
- Agency cultures and work practices that made interagency and interprofessional negotiations difficult.

#### **3.3.4 Workforce development needs for self-neglect practice**

Participants gave extensive feedback on the range of workforce development needs related to self-neglect practice. The needs themselves were seen as extensive and complex, perhaps reflecting the complexity inherent in the work itself, and the diversity of challenges encountered. The findings here fall into two distinct categories: priorities related to development of the *workforce*, and priorities related to development of *workplace*, by which is meant the structures, systems, processes and patterns of the workflow of self-neglect work. These two categories, whilst distinguished here for clarity of reporting, were seen as inherently linked: “*we won’t know all the workforce development needs until we’ve resolved some of the systems and service issues*”. The findings of this section may be found in tabulated form at Appendix 3.

##### **3.3.4.1 Workforce development needs**

###### **a. Knowledge about self-neglect**

There was a strong appetite for what was described as core knowledge about self-neglect—its symptoms, causes and risks, and the complexity of factors that could contribute to the overall picture. Linked to this was the question of definition:

*“It would be good if we could all agree what it is – definitions, outcomes – I don’t think it’s ever been mapped out properly.”*

It was recognised that a range of underlying conditions could be present. Practitioners needed information, both about the conditions and their likely impact on presentation and attempts at intervention. This would enable them to respond to the complexity, or at

least to understand it. Important here was core knowledge about the impact of mental capacity, or the lack of it, and the possible impact of traumatic life events, including loss and bereavement. Equally, an understanding of the philosophical and ethical territory in which self-neglect practice took place was considered essential. This related, in particular, to the positioning of ‘respect for autonomy’ and ‘paternalism’ or ‘duty of care’ at opposite ends of a moral spectrum.

### **Summary: knowledge about self-neglect**

- Definitions, symptoms, causes, risks.
- Complexity of factors.
- Obsessive Compulsive Disorder (OCD) and other associated conditions.
- Impact of capacity.
- Impact of loss and bereavement.
- Philosophical and ethical background (autonomy).

#### **b. Knowledge about interventions**

A major perceived need was for knowledge about interventions in self-neglect, and for that knowledge to be informed through research evidence. Assessment of risk was seen as a core element for practitioners in certain settings, along with knowledge of the legislation that could be used to frame interventions:

*“What statute can be exercised in order to ensure social workers don’t give up on a duty of care? The full range of legal interventions needed to be considered, along with the ability to weigh up different options that allow duty of care alongside human rights and autonomy.”*

In some organisations the breadth of adult social care work undertaken by teams could result in workers feeling they were not expert in anything, because the teams are so generic, and as a consequence legal knowledge could be spread thinly.

Knowledge about psychosocial interventions was seen as being important, yet perceived as a major gap, and brief, solution-focused therapies were identified as potentially of relevance to staff in a position to lead on therapeutic interventions. Some prioritised counselling approaches, and the ability to work from a strengths-based perspective. It was recognised too that working in long-term support mode brought its own challenges, requiring understanding of what might be expected from a slowly emergent pattern of change. Better understanding of the likely long-term pattern would,

it was thought, help to mitigate feelings of failure for staff more accustomed to seeing people “do better”. Equally important was knowledge about modes of intervention that may focus on damage limitation or harm reduction:

*“Forget the overwhelming bigger picture, and look at what we can do to make someone safer, as that can give the basis for future engagement.”*

Participants strongly endorsed relationship-based practice as a mode of intervention. Alongside this was a need for a knowledge base to enable holistic understanding of the person and the possibility of change through relationship:

*“The important bits are perseverance, relationship, and although we know their importance we haven’t really built them in to our training plans; we shouldn’t be making assumptions that staff do those things well naturally.”*

A further need was the development of ‘positive risk taking’, which means interventions that are framed in full awareness of the risks involved in various options, and which recognise that risk-free options are rare.

Despite the demand for knowledge about interventions, there was recognition that there is no one way of working. Interventions were likely to involve an amalgamation of different approaches, combining both psychosocial and practical ends of the spectrum. There was certainly a sense of reality about there being no one ‘magic bullet’:

*“You have to be creative, get engagement with the person, and there is no way you can do that without creative thinking and having a holistic view.”*

This led naturally to consideration of skills, know-how and professional role-based confidence, explored in more detail below.

Linked to knowledge of interventions was the question of knowledge about local systems. It was considered important that the more practical knowledge base should not be neglected:

*“What are the local resources you can call upon? Theory and insight, and communication, are OK, but you still need to act, and be clear about roles and responsibilities.”*

Clear priority needs were: knowing how local services work and awareness of what services were available from a range of agencies. Participants emphasised the

importance of knowing the system they were working in, and knowing how to make it work for their clients. To this end, there was some support for the creation of policies, procedures and guidance specific to self-neglect. Only two of the participating authorities had these, although participants from a third felt such documentation would be helpful. Others were less sure, preferring to see self-neglect integrated within core processes and protocols.

### Summary: knowledge about interventions

- Assessment.
- Legislation.
- Psychosocial interventions.
- Brief and solution-focused therapies.
- Harm-reduction approaches.
- Positive risk-taking.
- Relationship-based practice.
- Counselling.
- Long term support strategies.
- Knowledge of systems and practical services available - who can do what from the interagency network.
- Demand for procedures and guidance specific to self-neglect.

#### c. Skills and know-how

Alongside knowledge, participants were keen to emphasise the importance of skills and 'know-how' relevant to self-neglect work. Top of many people's list was the issue of capacity assessment, less from the knowledge point of view than from the skills and capabilities perspective.

*"We need to be comfortable in doing capacity assessments and be able to live with their consequences." "We need more support on mental capacity assessments; they're a cause of anxiety on how to make them decision-specific."*

The question of executive capacity, (the ability to implement a decision), as opposed to decisional capacity (making a decision or expressing an intention), exercised many practitioners: *"we fail to check out the ability to enact decisions"*. Equally, the sequencing of capacity and best-interests decisions, the quality of recording and the use of documentation required further development:

*“Assessments are not robustly evidenced. And mental capacity can be seen as a fixed attribute, rather than decision specific.”*

Relationship-building skills were also seen as vital—joining and engaging in ways that recognise the individual circumstances:

*“Having a foot through the door is the most important thing, and getting a relationship to build a position of trust, not appearing judgemental and saying we need to sort your life out...People forget they have the skill to build that relationship—the outcome is getting in through the door.”*

This was also seen as allied to curiosity about people’s histories, and patience to let them unfold at the client’s pace; the *“loving firm approach of workers who can succeed in making engagement and getting in”* was seen as of equal, if not greater, importance than the provision of practical solutions.

Skills in risk assessment were important: *“we can see things more or less risk laden than they actually are”*. Equally skills in decision-making were to be prioritised. Such skills were particularly important in the context of the need to weigh the pros and cons of conflicting imperatives, such as respect for autonomy and duty of care, and achieve a balanced decision on ways forward that pay due regard to both.

Working with low motivation and resistance was perceived as a further skill development need: *“you’ve really got to try and see where that person is coming from”*. This was seen as different from empathy: *“finding that person’s motivation is the most important positive starting point”*. Allied to this, negotiating skills were equally important, applicable in two directions – in direct work with the client and to support collaborative practices with partner agencies.

### **Summary: skills and know-how**

- Assessing capacity.
- Joining and engaging.
- Working with resistance and low motivation.
- Patience.
- Person-centred communication.
- Negotiation skills—creating change through relationship.
- Decision-making that balances conflicting imperatives.

#### **d. Professional, role-based confidence**

The skills outlined above support a key attribute that was valued and prized by participants – the ability to follow one’s own professional counsel to find a pace and style that facilitated the exercise of creativity, which could move away from proceduralised practice towards framing outcomes that were person-centred. This was seen as particularly important for social work:

*“Social work has lost the sense of its overall responsibilities, the focus has been on the proceduralisation of safeguarding rather than the overall role as a social worker...(we) need to rebalance social work back towards ‘proper social work.’”*

Core to this, was the ability to be confident in professional judgement:

*“You need the ability to engage in judgements that are unpopular, and thereby build confidence to stand out against majority views about what should be done”.*

Allied to this was the recognition that self-neglect work was inherently unsettling and contested:

*“Sometimes practitioners think there’s a right and a wrong, and if they do right there’ll be a happy ending; but we need to get more of a feel of the uncertainty of the world and be comfortable with that.”*

#### **Summary: Professional role-based confidence**

- Ability to follow own pace and own style.
- Exercise freedom and creativity of approach.
- Move away from proceduralised practice.
- Ability to frame person-centred outcomes.

#### **e. Professional values and perspectives**

Professional values were seen as an important component of self-neglect practice. First, self-awareness on the part of the worker was viewed as vital in order to maintain a distinction between one’s own lifestyle standards and those of others. This core non-judgementalism was seen as important to a position of tolerance for lifestyle choices. It was not, however, a ‘laissez-faire’ position, but rather the foundation for a sophisticated understanding of thresholds. It is the ability to recognise and rationalise circumstances in which client choice reached a risk-laden tipping point. Second, professional values

were seen as important to how power was exercised in work with self-neglect. Legal rules that could be used in different ways to coerce compliance were seen as requiring strict adherence to professional codes that emphasise the importance of partnership working and involvement. Again, this was not to reject the availability of coercion, but to ensure its thoughtful and careful application where deemed necessary.

### **Summary: professional values and perspectives**

- Self-awareness.
- Respect for personhood.
- Non-judgementalism, tolerance.
- Ability to tolerate uncertainty and risk.
- Constructive use of power.

#### **f. Support and supervision**

Participants placed considerable emphasis on the value of support and supervision as two key components of workforce development, the first more personally oriented, the second focused on practice development. There was strong recognition of the personal impact on practitioners of the self-neglect work they undertake, and of the importance of both informal and formal mechanisms for responding to it. The impact of witnessing the apparent loss of dignity of an individual, living in acutely self-neglectful circumstances was acutely stressful: “*my big cases of self-neglect, I would remember them for years*”. The work could be frustrating, engendering a sense of losing professional purpose:

*“Most of us can cope with conflict, challenges, tricky situations, if we feel we are being purposeful, and sometimes that can be lost.”*

Or conversely, successful engagement could bring its own emotional challenges:

*“There’s this issue of the emotional resilience and psychological well-being of someone who is supporting someone who self-neglects – you’re feeling great at first because you got them to respond to you, then that can turn into a real emotional burden because the responsibility falls on you, they place a lot of expectation on you.”*

There was recognition of the need to protect staff from burnout and to support their resilience, particularly where caseloads were comprised predominantly of challenging situations—this was seen as a key training need for managers.

The second aspect of supervision was that of developing practice, to be achieved through a range of mechanisms. These included regular meetings and handovers during shift changes, debriefing and support, casework supervision, and reflective practice sessions. The range of provision was seen as important:

*“With self-neglect you need a more flexible approach to how the work is overseen; you do need supervision, but also peer support and practice forums where people can engage in reflection and imaginative problem solving.”*

There was a strong preference for case discussions to be multi-disciplinary, although accompanied by recognition that this was difficult to achieve.

### **Summary: supervision at two levels**

#### Support:

- personal impact of the work
- frustration
- emotional burden
- preventing burnout
- building emotional resilience.

#### Practice development:

- reflecting on experience
- discussing approaches
- use of peer supervision, practice development forums
- legal advice
- ‘proper social work’.

#### **g. Interagency and interprofessional partnership working**

In most cases of self-neglect, practitioners were thought likely to require networking and negotiation skills to enable them to work effectively in collaboration with other professions and agencies:

*“The local authority doesn’t own self-neglect, everyone has a responsibility in it; you don’t get to say that’s the LA’s business, awareness goes across the board.”*

Beyond the skills of the individual were wider perspectives on promoting a shared ownership of self-neglect. The systems and mechanisms involved are covered in more

detail below, but in relation to workforce development they require approaches that can successfully convene systems, negotiate between the parties and recognise the diverse contributions of a range of participants.

#### **Summary: interagency and interprofessional partnership working**

- Knowledge about the recognition of diverse contributions.
- Negotiation skills.
- Convening systems.

#### **h. A learning culture**

Crucial to workforce development was the existence of a learning culture, at individual, team, service and organisational levels. This was seen as having a number of components. It included the provision of learning and development resources and time to use them. Participants also wanted dissemination of research evidence as it becomes available, including: briefings on the outcomes of complaints, management reviews, ombudsman judgements and serious case reviews from their own authority and elsewhere. The learning culture would also use feedback from service users and carers. Finally, it would have systems for embedding learning from practice in both workforce development and organisational development planning. It was recognised that many practitioners would have a strong ethos of personal responsibility for continuing professional development, but that this should also be facilitated and supported through organisational systems.

#### **Summary: a learning culture**

- Organisation, team, individual levels.
- Use of feedback from service users and carers.
- Learning from practice embedded in workforce development and training planning.
- Resources to support own research and development.
- Briefings on outcomes of reviews: management, serious case reviews, complaints.
- Time to make use of them.

#### **i. General considerations**

In considering the workforce development priorities outlined above, participants often differentiated between job roles and levels of responsibility when discussing priorities.

For example, the focus for managers may be different from that pursued for front line staff. Similarly, the needs of professional qualified staff, with particular job roles, may differ from those of support workers and others with practical, hands-on responsibilities. An effective workforce development strategy would target initiatives at the appropriate levels in the organisation, matching carefully to job role.

Equally emphasised across all the domains was the importance of multi-agency workforce development strategies, and of multi-agency training in particular. This was seen as facilitating the development of common ground, and to create the kind of networks in which staff from different agencies could see the value of joint working.

Emphasis was placed too on the importance of longitudinal approaches that took into account career stages. An example is social work, with its initial qualifying education, newly qualified and assessed year in employment status, and continuing professional development through the Professional Capabilities Framework (TCSW, 2012). Thus workforce development in the employment context was a continuum. Important too were opportunities for putting learning into practice:

*“Some training lacks strategies for people to build on knowledge-based training by following up with practical strategies that will be helpful for staff in making the most of the training, applying the learning to how do we work with people.”*

#### **Summary: general considerations relating to workforce development needs**

- The importance of targeting workforce development initiatives at the appropriate levels in the organisation – matching to job role – front line staff, managers.
- The importance of multiagency training—learning to do things together.
- The importance of longitudinal approaches, taking account of learning and development at qualifying, newly qualified, and continuing professional development levels.

#### **3.3.4.2 Workplace development needs**

Beyond the direct remit of workforce development, but crucial to its effectiveness, are two key elements of workplace development: service culture and risk management. These are considerations related to the structures, systems, processes and patterns of the workflow of self-neglect work.

### **a. Service culture**

First is the perceived need for changes in the extent to which the service culture prioritises and values independence, to allow recognition of the need for different pathways for people who self-neglect:

*“We need to move away from a culture of services geared to independence and the assumption that the role of staff is to promote it”; “we need to be able to provide ongoing support for complex clients who don’t fit into the two year independence pathway model.”*

This involves re-negotiation in some cases of what is meant by outcomes, and recognition that cases of self-neglect may not achieve standard outcomes or solutions, but require a more flexible set of expectations: *“self-neglect won’t fit into the clusters of outcomes to which care packages are geared”*. Equally, practitioners may redefine what they seek to achieve:

*“How do we define a successful outcome? Someone may be cleaner and warmer, but what about their quality of life as they would define it?”*

A move away from universal expectations of independence entails also a potential change to commissioning practices to enable providers to support clients in the longer term without a cut-off point that provokes a crisis, such as eviction.

The second issue related to service culture, which is linked to the question of an alternative outcome to independence, is the need for approaches that allow time and space for long-term, ‘slow-burn’ work: *“the best way to cut costs for some people is to have low level support for a long time”*. Procedurally driven assessment and intervention were seen as limiting flexibility:

*“More time is needed with these cases; it needs an organisational space for that kind of approach.”*

*“Every situation is so different, and sometimes it looks to managers as if nothing is being done, you’re just going with the flow of the person to get a real measure of the situation—once you have that you can map and plan the features of the way forward. We underestimate how much thought and analysis has to go into it.”*

Organisational tolerance of an approach where little tangible change appears to be achieved allows what was described as a *“casual but purposeful”* approach. This

enables, through a continuing relationship, the possibility of an ongoing review of needs, risk, mental capacity and service acceptance.

The third aspect of service culture deemed to be of importance was the need for a system that allows a response to self-neglect cases that fall below the eligibility threshold for adult social care:

*“We need to have service structures that allow appropriate responses – i.e., not just signposting, self-neglect needs a response – we have to be able to support people to do that work.”*

This might entail review of how eligibility criteria are conceptualised and applied:

*“People who self-neglect are often very isolated, not living in sustainable family or community structures, and isolation is significant in our FACS [Fair Access to Care Services] system, so we need to consider how we address isolation.”*

#### **Summary: aspects of service culture**

Review of the extent to which services are geared to independence:

- a need for different pathways for complex clients who do not meet the “two year pathway to independence” requirements
- re-negotiation of what is meant by outcomes
- review of commissioning practices with voluntary organisations.

A different approach that gives time and space for long, slow-burn involvement:

- doesn't rush things or make barriers from entry criteria that people who self-neglect aren't going to meet
- no worry if it looks like nothing's being done
- permits keeping in touch in a casual, but purposeful, way
- the possibility of 6-monthly reviews even if cases are 'dormant'.

A system for cases that fall below the eligibility thresholds for adult social care and for whom the usual response of 'signposting' to other services is not appropriate.

#### **b. Risk-management and decision-making structures and processes**

The second key element of workplace development is the perceived need for ways in which practitioners and managers from a range of agencies can come together to share

information. This would result in a joined-up and holistic view of an individual's needs, considering options for intervention, allocating responsibilities and coordinating responses. It was anticipated that such systems could expose interagency differences in thresholds and expectations. However, the value was perceived as the opportunity to use those differences to work towards shared and better informed positions on risk and intervention:

*“We need a forum or panel to which cases can be brought; it's impossible to work with on your own, you needs others' perspectives, to talk cases through, set realistic goals, move away from [a] 'solve it now' model of intervention; agencies must recognise their role in working with these cases.”*

Equally importantly, such systems were seen as providing evidence of a shared ownership of self-neglect, deemed particularly important given its complex ways of being caused and manifestation:

*“It's a move away from saying 'well, you own that bit', so we collectively own what happens with that person; even in the best cases, it's always about who owns what bit—it should be about everyone being responsible.”*

Shared ownership was important to avoid any particular case becoming passed from agency to agency without coordination:

*“We need to prevent cases becoming a 'hot potato', ensure discussion and liaison. There is strength in taking collective decisions.”*

The *multi-agency risk assessment conference* (MARAC) model, used in situations of domestic abuse, was mentioned by a number of participants. It was seen as a helpful approach in achieving consensus about what can be done in any particular set of circumstances, even if that consensus is for no intervention.

## Summary: risk management and decision-making structures and processes

The need for a decision-making hub or panel that can:

- share information
- give a joined-up and holistic risk view
- consider options
- decide who will do what
- enable early intervention
- co-ordinate responses
- Ideally this would be interagency “we should all collectively own it” (like MARAC).

### 3.3.5 Perceived challenges of workforce development for self-neglect practice

There were a number of perceived challenges to progressing and implementing workforce development, in relation to self-neglect, which emerged from discussions with participants. . The first of these related to the recognition that change cannot be made through workforce development alone, and particularly not through training, in isolation from organisational development. Equally, training itself was seen as only the start of a process of practice development:

*“We have these trainings [sic] but we forget about them,” “training is fine, but it’s putting it into practice that makes it stick.”*

Transferring training to practice is fraught with difficulties, and as noted by Pike et al (2010) is related to a complex interplay of factors: pre-training and learner characteristics, training design and delivery, and workplace factors.

*“When staff were asked what helped or hindered them [in practice], they rarely mentioned training, it was all about safeguarding procedures, staffing, workloads, communication problems between multidisciplinary teams.”*

*“Training can be seen as the ‘easy option’, rather than addressing the underlying issues.”*

The sheer range of job roles and positions in which practitioners could encounter self-neglect made any workforce development framework extremely complex. There was recognition that generic short training courses delivered to everyone across the range of relevant groups, such as in the example given of mental capacity training, had a number

of shortcomings: “we’ve got to target it right, you’ve got to know the audience”. Equally, differences in learning styles needed to be catered for.

Engagement in workforce development initiatives for self-neglect was perceived as variable:

*“There is a bubble of people who think we really need this, but there are also groups who won’t recognise that it has something to do with them; there will still be a gap, and we need to get that message out.”*

It could also be difficult for agencies to release staff for training and practice development initiatives, and the high turnover within some workforce groups could make it difficult to build up a critical mass of sustained expertise.

The current heightened interest in self-neglect, fuelled by high profile cases and by television profiling of self-neglect issues, first of psychological intervention with hoarding behaviour, and subsequently of obsessive compulsive cleaning, was seen to be a mixed blessing. As well as raising awareness, it had perhaps also given rise to misconceptions and myths about ‘what works’.

The very individualised nature of self-neglect work, in which intervention must be carefully negotiated and matched with clients’ choices and tolerances, also posed perceived challenges, in that training could not rely on the delivery of standard interventions. Instead it required a more nuanced approach that sought to develop a wide variety of knowledge and skills that could be relevant in individual situations. The infinite variability of presentation and causation of self-neglect was seen as inevitably throwing practitioners back on the exercise of their own relationship-building, professional judgement and decision-making skills in the context of seeking a ‘least bad’ alternative.

One concern expressed by several authorities was about the lack of evidence for the effectiveness of workforce development initiatives in general, not confined to those in self-neglect. The discussion on this related specifically to the challenge of tracking the outcomes of training, particularly the degree to which it translates into practice and how that practice then impacts on client experience and outcomes. One authority was about to embark on an exercise with users of safeguarding services, attempting to gain their voices and perspectives on the work undertaken. It was recognised, however, that attribution of outcomes to particular training undertaken by workers would be difficult to achieve.

Equally, there were questions about how workforce development initiatives, and particularly training, could be funded in the context of other priorities, and recognition that the absence of outcomes evidences and cost-benefit analyses made the business case difficult to establish.

### **Summary: challenges of workforce development for self-neglect practice**

It was widely recognised that the development of practice in self-neglect could not be achieved through workforce development alone. Organisational development was also seen as vital to ensure structures, systems and mechanisms are in place to facilitate good practice. Training had a contribution to make, but its successful transfer to practice required attention to a range of factors, including the characteristics of the learners and the organisational context for practice.

Challenges were seen to arise from the range of roles practitioners play in different contexts, and the tendency for self-neglect to be seen as ‘someone else’s problem’. A standard interventions approach to practice development would not work, as support is very individualised, with strong reliance on relationship-building, professional judgement and decision-making skills.

A perceived lack of robust evidence of the outcomes of workforce development was thought to make it difficult to select approaches that would be effective.

A perceived lack of robust evidence of the outcomes of workforce development was thought to make it difficult to select approaches that would be effective.

### **3.3.6 New initiatives reported in workforce development for self-neglect practice**

In addition to views on workforce development needs, the interviews and focus groups sought information about initiatives already taken or underway. These are reported here using the categorisation introduced earlier to distinguish the interconnected domains of *workforce* development and *workplace* development.

#### **3.3.6.1 Workforce development initiatives**

##### **a. Training**

The majority of participants did not know of any specific workforce development initiatives specifically targeted at self-neglect work in their authority or agency, although, as mentioned in the earlier section on the challenges of the work, some training

provision had clearly been made. For example, most staff had had the opportunity to attend training on related issues such as mental capacity, safeguarding, mental health, autism, communication skills. Some had undertaken courses on hoarding and OCD. Specialist services had sometimes been brought in to provide advice to accommodation support keyworkers on approaches to be taken in self-neglect. Legal advice was made available to practitioners seeking options for statutory intervention. A number of examples were given of training initiatives on safeguarding, which will nonetheless draw attention to self-neglect, for example the production of a short film to raise the awareness of staff who could be the first observers of potential harm to a vulnerable adult, in which self-neglect will feature as an issue of concern.

**b. A strategic approach**

One authority had started to develop a training strategy linked to interagency procedures and guidance for staff on self-neglect. Taking place under the auspices of the Safeguarding Adults Board, both the guidance and the training strategy reflected the emphasis on joined-up thinking and decision-making that characterises the ethos of the board. The training strategy took as its starting point the mapping of professionals and agencies that have contact with people who self-neglect, their role, and their needs for either raised awareness or training to fulfil positive obligations. Levels of required knowledge emerged as strongly related to role, and the level of support likely to be provided within that role to the self-neglecting individual. Thus the training needs could be seen as tiered, with the training itself intended to reflect the level and nature of involvement at each tier:

- level 1: those who have occasional or one-off contact
- level 2: those who actively support with daily living or have sustained contact
- level 3: those involved in assessments and decision-making
- level 4: those involved where level 3 involvement results in referral higher in organisational structures.

Further details of the framework may be found in Appendix 4. The approach was evidence-based in that it has been informed by research findings, by the outcomes of serious case reviews, and by practitioners' views in self-neglect workshops held in the authority. Although undertaken under the auspices of the board, the approach had been to reach out well beyond the range of agencies involved in the board, and to consider how wider professional and community groups, and indeed charitable organisations, such as the RSPCA, might need to be involved. At this stage, the framework was focused on training input, and not linked to mapping of competences or outcomes, although it was recognised that such mapping might be a future development.

**c. Practice development**

One authority described the existence of professional development groups for advanced professionals and practice educators, to which cases could be brought for discussion. These would enable the development of understanding and ideas of intervention. The same authority was considering the implementation of action learning sets to provide a more sustained and structured approach that could be specifically targeted on self-neglect work.

**d. Mental capacity assessment**

Arising from a need to evaluate implementation of the Mental Capacity Act 2005, one authority reported having embarked upon an audit of mental capacity assessment practice. The exercise is in two parts: a questionnaire seeking practitioners' self-ratings of understanding and confidence, and a randomly selected audit of cases. It will lead to further practice development initiatives, if warranted. Examples might include practitioner 'surgeries' for consultation on difficult capacity decisions and the opportunity to shadow experienced practitioners. It may also provide stronger evidence for the commissioning of specific approaches to mental capacity training.

**e. Broader workforce initiatives**

Further examples of workforce development initiatives, although not specific to self-neglect, were the implementation of authority-wide initiatives using the Professional Capabilities Framework (PCF) (TCSW, 2012), to facilitate personal development planning for qualified social workers. In one authority this involved using the PCF as a means of identifying strengths, skills and development needs, with a view to planning onward continuing professional development trajectories. In another, the PCF was to be used as a framework for supervision. Linked to this was a move to re-shape elements of the workforce. Examples include two authorities appointing lead practitioners who work alongside practitioners to support and develop practice. These lead practitioners have expertise in challenging practice areas, including self-neglect work,. The appointment of a Principal Social Worker for Adults, with practice development as part of their brief, was also seen as providing opportunity for self-neglect work to be profiled within core organisational structures and processes.

**f. Support and supervision**

Support structures for staff engaged in challenging work were commonly reported. These included the opportunity to debrief formally from traumatic engagements, beyond more routine provision of either informal support from colleagues or supervision, thus moving away from a purely workload management approach. Three authorities reported the introduction of new models of supervision, in one case involving both group and individual meetings and supervision contracts that framed supervision as a right, in the

context of an open-door policy. It was deemed important to combine top-down and bottom-up approaches to recognising stress levels, create a supportive environment, and have core involvement of managers who remain close to practice. Social workers and other professional practitioners were making active use, in some authorities, of adult safeguarding specialists for advice and guidance.

### **Summary: Workforce Development Initiatives for Self-neglect Practice**

- Training on related issues such as mental capacity or safeguarding was not uncommon, and advice was sometimes available from specialist services.
- One training strategy took a tiered approach to training needs for self-neglect work, with the training content reflecting the nature of staff involvement at each tier, from one-off contact through to complex decisions.
- Practice development groups were used to facilitate discussion of challenging cases.
- An audit of mental capacity assessments was taking place in one authority with a view to this informing further practice development initiatives.
- Broader workforce developments, such as the use in supervision of the PCF, or the creation of new roles, could incorporate work with self-neglect.
- Support to deal with the emotional impact of the work and supervision to develop thinking on practice were both prioritised.

#### **3.3.6.2 Workplace development initiatives**

A number of initiatives were being taken in relation to systems and processes within and between agencies.

##### **a. Interagency guidance**

Two authorities described the development of procedures and practice guidance for staff on self-neglect. They were creating pathways for cases that otherwise might travel with difficulty through interagency systems. In one case, a two-tier approach was advocated that would involve a response from both the initial agency raising the concern and the more specialist involvement of adult protection; a range of legal options was identified, and a multi-professional meeting was a core element of the approach. In the other, as described above, the guidance was to be launched alongside a training strategy that would support its implementation.

## **b. Interagency communications and decision-making**

A number of examples involved structures for interagency communications in particular contexts, such as tenancy loss or fire risk. One example was a self-neglect panel convened to enhance the tenancy support role by facilitating information sharing and action planning. It aimed to maintain tenancy stability, where threatened by self-neglect of the individual concerned:

*“We have set up a self-neglect panel that consists of multi-agencies and departments to explore what joint action can be taken to deal with those complex cases where tenants will not engage, and to establish an action plan”.*

Another example was the setting up of an interagency panel to evaluate and respond to high fire risks. With representatives from adult social care, environmental health, mental health, older people’s mental health, housing, the fire brigade, voluntary organisations, police, substance misuse and probation, the panel holds a monthly meeting, to which cases can be referred for discussion. Outcomes and learning are fed back to the Safeguarding Adults Board on a six-monthly basis, and fed back into teams through information networks of practitioners. The response from practitioners was reported as very enthusiastic: *“this is real support for people doing difficult casework”*. Arising from the work of the panel, and from work in other high-risk cases, a best practice manual is to be produced with the intention that it will act as a staff development resource for practitioners across the authority. The panel also has plans for a large-scale, multi-agency conference on fire awareness training, at which ‘top tips’ for self-neglect work will be profiled, alongside other learning of value to practice development.

## **c. Changes in staff roles**

There were other examples of developments in practice that involved moving outside routine expectations of staff roles:

*“We have cleaners involved in one to one sessions with residents; it's not part of the cleaners’ job, they would usually look after the communal areas only, but because they have a good relationship they can carry that into individual cleaning support”.*

Keyworker involvement could, on occasion, be extended to involve a second keyworker in order to meet specific needs.

## **d. Ongoing case review**

Within adult social care, one agency described the introduction of a system to engage in a six-monthly review of cases. This would include cases that had either been closed or made dormant, as a result of lack of engagement or service refusal, but where review of risk and capacity could provide indications of possible future need for intervention.

**e. Broader practice developments**

In other cases, practice initiatives not specific to self-neglect were described because they were seen as holding potential for transfer of thinking across to self-neglect work. One example was a pilot project working with young adults with complex and chaotic lifestyles who otherwise slip through the interagency net. Intensive work undertaken with a small number of individuals was reported to have achieved very promising results. Another example involved an initiative to reduce repeat referrals in safeguarding. It intended to develop an understanding of more sustainable interventions through exploration of previous interventions, and reasons they did not resolve the safeguarding concern.

Several authorities reported having moved away from former models of practice (described by some as care management) to place the client at the heart of what is done and not allowing barriers to arise from the ways in which services are organised. One example was more flexible staff engagement at the point of hospital discharge, which allows hospital-based staff to work through a client's period of reablement to continue the benefit of the relationship already built. Another example was an emphasis on relationship-based practice, supported by training on building rapport, attachment and trust.

**Summary: workplace development initiatives for self-neglect practice**

- Interagency guidance was being developed, creating pathways for self-neglect cases.
- A number of examples involved structures for interagency communications and decision-making in particular contexts, such as tenancy loss or fire risk.
- Expectations of staff roles were more flexible to accommodate the needs of people with self-neglectful behaviour.
- Routine review of closed cases, where service refusal had been a feature, was being implemented.
- Broader service developments could create learning relevant to self-neglect work.
- Examples included a service targeting young people with complex lifestyles, a focus on repeat referrals in safeguarding, and a move away from strict limits on the time involvement of staff in hospital discharge.

### 3.3.7 The costs and benefits of self-neglect practice and of workforce development initiatives

There were no data available on the costs and benefits of self-neglect work, or of investing in workforce development initiatives on self-neglect. Some authorities indicated known costs associated with specific self-neglect interventions. For example, the daily cost of cleaning a property in one authority was £750, and could well extend beyond one day. Such interventions were sometimes necessary as a precursor to other essential work: *“properties often need to be deep cleaned before a contractor will carry out repairs”*. These interventions were made in the knowledge that, even with support, the tenant’s behaviour is unlikely to change and that repeat costs will be incurred. It was estimated that the cost of investment in hostel and accommodation provision was about 20% of the cost of someone who is self-neglecting being homeless, and that preventing a death on the street brought a saving of £1m.

The cost of support worker involvement was estimated to be 30% more than for other clients because of the intensity and involvement over a longer period of time. Equally, such cases were likely to require a greater investment of supervision time, both for the worker and for their manager.

In the absence of cost-benefit data, participants drew on common sense to argue the case both for intervention and for workforce development initiatives. Responding to self-neglect in accommodation services was a necessity in order to prevent:

- the decline of the condition in accommodation
- accommodation becoming deeply unattractive to those who need to live in it
- staff becoming demoralised
- service users slipping through a net that could at least contain them in relative safety.

*“When there a certain number of people who self-neglect (in a property) the knock-on effects are quite dramatic.”*

In one authority, the introduction of an interagency panel to share information and plan interventions had reduced the number of very high-risk cases to around 17% of their previous figure:

*“There is great good in doing this work because with some sort of intervention the benefit is enormous; you don’t have to evict, people don’t end up in hostel provision, people can stay in their own homes for longer, they get the healthcare intervention they need, properties can get heated and repaired”*.

## Summary: the costs and benefits of self-neglect practice and of workforce development initiatives

There were no data available on the costs and benefits of self-neglect work, or of investing in workforce development initiatives on self-neglect. In the absence of cost-benefit data, participants drew on common sense to argue the case both for intervention – particularly approaches to contain risk – and for workforce development initiatives.

### 3.3.8 Perceptions of the role of Skills for Care

The wide range of participants, many from practice and others from more specialist training and workforce development roles, inevitably meant that knowledge of the work of the sector skills council, Skills for Care, was variable. Indeed there was recognition that knowledge of its possibilities was not widespread: *“I should know more about Skills for Care than I do”*.

Given a brief explanation of its national role and remit, many participants continued to prioritise the need for provision of training materials. They articulated a need for nationally available training courses on self-neglect or, failing that, materials such as training manuals, e-learning resources and videos that were suitable to be incorporated within local training initiatives. Reference was made also to the role of the Social Care Institute for Excellence in this regard: *“a knowledge bank that brings research and understanding to people’s notice”*, with the research and good practice guidance already available perceived as having a high impact. Equally, there was a perceived need for further information to support workforce development practice:

*“Serious case reviews are very helpful, and having messages in cases of self-neglect gathered from across authorities would be very helpful.”*

A number of participants also expressed the need for some kind of national forum on self-neglect, pointing to the value of sharing initiatives, research and resources that may be developed locally but have a wider application. Both real-time and online meetings were thought to be of value. Knowledge of existing resources that can perform this function, such as the Local Government Association Knowledge Hub, was limited, although it may be the case that the overt focus on safeguarding was deemed to obscure self-neglect issues.

Those with more specialist knowledge gave a more targeted account of the role that Skills for Care could play in promoting workforce development in self-neglect. There was a perceived need for information and advice to employers on the priorities for workforce development in this field. The lack of a competence framework for self-neglect work was recognised, although there was some ambivalence about whether such a framework would be helpful:

*“What won’t be useful is a list of things people might need to know or do when working with self-neglect; it needs to be more nuanced than that”.*

Authorities who had worked closely with Skills for Care on other initiatives were enthusiastic about the prospect of a national lead that could link authorities up with each other to share expertise, provide a critical friendship role, support pilots and disseminate best practice guidance on workforce development issues.

#### **Summary: perceptions of the role of Skills for Care**

- There was not widespread knowledge of the potential of the role of Skills for Care.
- Participants considered that national leadership could stimulate the provision of self-neglect training materials, and take a consolidated approach to disseminating relevant research and findings from serious case reviews.
- There was a perceived need for information and advice to employers on workforce development priorities. There was some interest in a competence framework that could take account of the nuanced nature of practice.
- Participants would also value a critical friendship role, support for pilots and dissemination of workforce development best practice guidance.

### **3.4 Discussion of the findings**

This section reflects on the findings, and considers in particular the implications for training initiatives and for existing training and practice development materials on other topics provided by Skills for Care.

Self-neglect was clearly perceived as a complex challenge by many of those interviewed, and accordingly caused difficulties for staff and for organisational cultures. While work on self-neglect is in its infancy in the localities in which interviews took place, and nationally if the lack of research literature can be taken as an indication, there are glimmerings of development initiatives emerging in different areas. Such

initiatives include the creation of inter-agency panels, the development of strategies and procedures, and measures to enhance professional development support and training.

Cost-benefit analysis has proved difficult, although it could potentially assist with the concerns some interviewees reported about getting staff and agencies to prioritise learning around self-neglect, when it may not be part of safeguarding and could be seen as “*just another chore.*”

With regard to the possibilities for wider support from a body such as Skills for Care, some had doubts about the utility of a competence framework set out as a form of checklist, but recognised the value of having national guidance on learning priorities. An opportunity for more widespread sharing of good practice through a national forum was suggested. Many felt that provision of training and development materials would be a valuable contribution. Interviewees also raised a number of concerns about the challenges of ensuring that training would be effective, which mirror those that can be found in the literature in respect of training on related issues such as safeguarding. These challenges are discussed further below.

### **3.4.1 Training effectiveness**

Specific training on self-neglect and related issues was mentioned by a number of respondents as a first step in workforce development, and is frequently a recommended outcome of serious case reviews. However, interviewees also expressed a number of concerns about such training courses, including:

- the challenges of ensuring that self-neglect training would be given sufficient priority among the many competing demands of the social care workforce
- the need for training to capture the nuances involved in the highly individualised presentations of self-neglect
- finding a balance between input that is generic and input that is specific to the different audiences within the social care workforce
- reinforcing and facilitating retention of learning after discrete training sessions
- whether training would be effectively linked to strategic planning
- the difficulty of meaningfully and reliably measuring outcomes and effectiveness.

Some of these issues also arise in relation to training in adult safeguarding. In particular, the question of how to measure impact is problematic and, consequently, rigorous evaluations of safeguarding training effectiveness are lacking in the UK context (Campbell and Chamberlin, 2012; Skills for Care, 2013).

What evidence exists is tentative and somewhat mixed. Low levels of training for staff have been found to be a risk factor for abuse or neglect (Faulkner and Sweeney, 2011; Skills for Care, 2013), suggesting that training in itself *is* effective, or that organisations providing more extensive training may have other, associated, characteristics that make abuse less likely, or both of these factors. Yet it is by no means the case that training interventions inevitably lead to improvements in practice (e.g., Cooper *et al.*, 2012; Pike *et al.*, 2010; Richardson *et al.*, 2002). Moreover, where studies have researched levels of knowledge about the law, mixed results have been found and concerns expressed about levels of legal knowledge and skills (Mackay, 2008; Preston-Shoot and McKimm, 2012; Preston-Shoot *et al.*, 2011; Campbell and Chamberlin, 2012). Clearly not all approaches to training are equally effective. Seminars in one study were found to be more effective than printed material in increasing knowledge and sound case management, with courses improving staff identification, recording and reporting of cases of abuse. However, training needs to be targeted to take into account participants' baseline knowledge if learning is to add to what people already know (Richardson *et al.*, 2002), backing up the concerns raised by some interviewees. More recently, Pike *et al.* (2011) found that having received training was, alongside confidence, correlated with making an alert, whereas knowledge of safeguarding was not. While this study focused on adult safeguarding rather than self-neglect in particular, and it is not yet clear if this finding is transferable, it is certainly suggestive of the importance of providing some level of training targeted on practice, which takes account of the work environment, rather than assuming that knowledge alone will be effective.

### **Summary: the implications for training initiatives**

- Training interventions do not necessarily lead to practice improvement
- Some training approaches can improve knowledge, but knowledge in isolation does not necessarily change practice
- The measurement of training outcomes is difficult, particularly those that related to impact on practice
- Transfer of training to practice can be enhanced where the work environment is receptive to practice development

#### **3.4.2 Existing development resources**

Given that a number of interviewees mentioned the provision of training materials as a useful contribution, it was of interest to investigate what materials are currently provided by Skills for Care. Potentially relevant existing development resources available through the Skills for Care website were identified, so that the extent to which they might provide

transferable input to self-neglect could be considered in the light of this report's findings. In addition to links through the Skills for Care Research Directory to external resources, these included:

- *Learning to Live with Risk: An introduction for service providers*  
([www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?IID=9974&sID=1030](http://www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?IID=9974&sID=1030))
- *Living with Risk: Keeping risk person-centred*  
([www.skillsforcare.org.uk/developing\\_skills/livingwithrisk/living\\_with\\_risk.aspx](http://www.skillsforcare.org.uk/developing_skills/livingwithrisk/living_with_risk.aspx))
- *Common Core Principles to support self care*  
([www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?IID=765&sID=58](http://www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?IID=765&sID=58))
- *Common Core Principles for supporting people with dementia*  
([www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?IID=9984&sID=2252](http://www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?IID=9984&sID=2252))
- *Evidence Review - Adult Safeguarding*  
([www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?IID=14554&sID=4065](http://www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?IID=14554&sID=4065))
- *Varsha – Safeguarding Vulnerable Adults*  
([www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?IID=2369&sID=915](http://www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?IID=2369&sID=915));
- *Outcome Statement 7 – Safeguarding*  
([www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?IID=2369&sID=915](http://www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?IID=2369&sID=915)).

While this is a disparate collection of material and there are inevitably risks of over-simplification in making any general observations about it, it was noteworthy that self-neglect was not explicitly addressed in any of these resources. Across all these materials, the importance of promoting autonomy and ensuring choice was strongly emphasised, as were appropriate risk assessment and management. There is guidance in *Learning to Live with Risk* on responsibility and liability relating to the duty of care. These are of significant relevance to working with self-neglect, but concerns arise that they do not encompass the full complexity of this area.

As the evidence review and interviews for this study have shown, self-neglect situations place a number of unusual and challenging demands on workers, and many feel that they are under-prepared in terms of understanding of its presentation, awareness of interventions and knowledge of the legal framework. There is extensive guidance and mandatory training on protection from abuse or neglect by a third party, in contrast with the sparse coverage of self-neglect. Yet reported in discussing the limits of training in isolation from the surrounding organisational systems, the existence of even these levels of provision for safeguarding training on abuse or neglect does not guarantee better identification or reporting (see Skills for Care, 2013; Campbell and Chamberlin, 2012). Meanwhile, many workers report unfamiliarity and doubt over what approaches, policies and values to draw on in self-neglect work (Braye *et al.*, 2011). Given how often training on adult protection fails to transfer into practice despite the more extensive input

it receives, it seems questionable whether staff will successfully translate guidance on the principles of safeguarding to what are sometimes quite distinct self-neglect cases, in the absence of explicit discussion or case examples. It is even less likely that they will successfully transfer this training into practice. This is a step which always represents a challenge to workforce development (Clarke, 2013), particularly when organisational culture is rarely geared to the sometimes long-term, slow-burn input needed for self-neglect. In the absence even of agreed definitions of what constitutes self-neglect, transfer is even less likely to occur.

In order to facilitate transfer more effectively, at a minimum, case studies based on self-neglecting clients, possibly drawn from relevant serious case reviews, should be provided within development resources. This might also serve as a basis to facilitate discussion of local procedures, information sharing protocols and networks that would be relevant, helping to bridge the gap between the training session and how it would apply in everyday practice. Serious case reviews repeatedly commented that staff too easily slipped into reactive mode, rather than exploring with clients the reasons for their refusal of services, and often failed to carry out comprehensive assessments or to co-ordinate effectively. While the development resources currently available through Skills for Care emphasise the importance of thorough assessments, for the most part they do not explore situations such as these, which might balance the emphasis on autonomy with a sustained, relationship-based and person-centred engagement with the person who is self-neglecting.

Any future resources on self-neglect from Skills for Care should address the need for *workplace* as well as *workforce* development. It was remarked by interviewees that training tended to work most effectively when it could be linked closely to practice. Development of action plans during training, to be put into effect afterwards, was suggested as a promising approach, but would clearly need support from management. The difficulties in achieving this were highlighted by one interviewee, who felt that: *“Where services are more focused on encouraging choice and independence, it becomes more of a battle against the ethos of their organisation – we commission someone because they’re very good at promoting independence, and then we tell them they have to curtail that independence in certain circumstances. It’s easy in safeguarding where they’re putting themselves obviously at risk with a perpetrator...there is a degree of social judgement in self-neglect, and it causes anxiety. That’s where the training gap comes in, giving people confidence to balance that duty of care.”*

While remaining alert to the importance of training at the individual level, this quote captures the significance of organisational culture and the pressures of competing value

positions. Commissioning, management and systems are seen as important in helping to ensure that the complexity of self-neglect is fully appreciated and taken into account by those working with it.

**Summary: the implications for existing Skills for Care material**

- Self-neglect is not explicitly addressed in the existing materials reviewed.
- Some of their content is relevant to self-neglect work. However, these materials lack explicit focus on self-neglect which makes them difficult to apply to self-neglect practice. Self-neglect case studies could usefully be incorporated within existing training and practice development materials on related topics.
- Given the significance of organisational culture for self-neglect work, future training and practice development materials should address the need for workplace development alongside workforce development.

## d) Concluding discussion

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That working with adults who self-neglect is a complex task emerges clearly from the evidence review, the findings of serious care reviews and the comments from focus group participants and interviewees. That practitioners and managers are working within a legal and policy vacuum may be overstating the case, but the complexity of the existing legal rules, for example surrounding mental capacity, and the dominance of personalisation, autonomy and self-determination within adult safeguarding social policy, create challenges that they struggle to work through.

It is clear, for instance, that striking a balance between accepting risky choices and challenging the decision-making of competent adults with capacity is experienced as difficult—what some participants referred to as the fear component. So too is knowing how, in individual unique circumstances, to strike the balance between autonomy and a duty of care—what some participants referred to as the choice question. Whilst waiting for change in the legal rules, including how self-neglect will feature within the Care Bill Code of Practice, workplace development can assist practitioners and managers by ensuring that practice guidance is available for working with adults who self-neglect. This can include when they disengage or refuse to accept services from agencies and when they take decisions that place them at risk of harm. Such guidance would need to include a definition of self-neglect and of thresholds that might trigger different levels of intervention. Such guidance is not, currently, routinely available.

The research found a distinction between authorities where self-neglect was dealt with within safeguarding and where it was not, in terms of mechanisms for investigation, decision-making, supervision and support. Both systems have advantages and disadvantages. Until such time as self-neglect is explicitly, in social policy and legislative terms, either included within adult safeguarding or within adult social care, thresholds that trigger assessment need to be clear. This is particularly important in cases where staff have become used to refusal of support and intermittent engagement, and therefore resolve to be reactive rather than preventively proactive. Thresholds for assessment are also important where there are multiple low level triggers that cumulatively might suggest the need for assessment but individually appear to indicate less critical needs.

Workplace development would be assisted if the findings of serious case reviews were routinely published, making them easily available to practitioners and managers, and if further research resulted in guidance about effective interventions in different types of cases of self-neglect. Such developments would be a welcome departure from the

present position. Here is one example of work that could be done by Skills for Care, SCIE or the Local Government Association, namely encouraging those agencies that are internally focused to be more outward facing, and providing resources to inform informal and formal discussions that are held within agency and multi-agency networks. Practitioners and managers have been clear that what helps to manage the complexities of self-neglect cases is formal (supervision, learning sets, panels, legal advice sessions, team meetings) and informal discussion, informed by easily accessible best evidence.

Accounts from focus group participants and interviewees identified just how crucial the attitudes and skills of individual practitioners can be. Some practitioners have clearly been prepared for the long haul of relationship and trust building. They seek, at the service user's pace, to understand how they are social, rather than necessarily rational, actors, with strengths and personal constraints, and support them to envision a different future. This work is not always successful. However, when it is, either with, or without, management and agency blessing, it demonstrates the potential of relationship-based practice. Training and supervision, the latter offered by peers as well as by managers, plays a key part in such skill development. So too does organisational culture, recognising, even within a care management system, that assessment of needs, risks and capacity is not a once and for all event, and that effective work with adults who self-neglect requires particular resilience and commitment.

Training, however, must be matched to the knowledge and skill set of those participating in it, and its messages must be supported and implemented by managers, as well as by participants if its benefits are to be realised. Supervision must be robust, ethically and legally informed, evidence-based in terms of self-neglect knowledge, and emotionally supportive. It must be timetabled into the working week. This raises the question of whether training in supervisory methods is available for new and experienced managers.

Training may seek to build capacity in terms of knowledge and skills, for example relating to mental capacity assessments, but this can quickly decay if it is not reinforced by practice that includes a learning component, perhaps through debrief and peer observation. Law updates can impart knowledge of, for example, the Court of Protection and inherent jurisdiction, but this requires consolidation through advice sessions with legal practitioners concerned with actual cases. Both can become frustrated by organisational systems that impede rather than facilitate the approaches that have a chance of making a difference in cases of self-neglect. This observation is mindful of the difficulty that training can take priority over other aspects of workforce development, and *workforce* development can take priority over *workplace* development. What is required

is the whole package of workforce and organisational development to build both the capacity and context for effective self-neglect practice.

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## Appendix 1: Literature search strategy

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A previous literature review (Braye *et al.*, 2011) had identified literature focusing on self-neglect from before 2009. Supplementary searches on the Social Care Online, Psycinfo and ASSIA databases were carried out to locate relevant material which had appeared since that date. Initially it was intended that studies would be included if:

- they focused on self-neglect
- took place in a UK setting
- dated from the year 2000 or after
- focused on either:
  - social care workforce development or training
  - the prevalence of self-neglect among the general population, or a sub-set of the population
  - the costs of unmet need caused by self-neglect.

Studies were to be excluded if they:

- used individual case study approaches (these studies would not be easily generalisable to answer the research questions of this evidence review)
- focused mainly on issues unrelated to the research questions driving this review (e.g., a focus on validation of rating scales; a focus on medical diagnosis or medication; a focus on abuse or neglect rather than on self-neglect)
- focused on qualifying student education rather than workforce development
- consisted of general recommendations for practice which drew on only the author's own experience or views.

Reading the titles and abstracts revealed that searches had located no literature that focused on self-neglect in relation to the workforce, and little that touched on training. Even in these cases, the focus on training was only minimal and did little to provide evidence of any sort. Consequently the focus of the searches was loosened and the search term 'self-neglect' alone was used, without further restrictions other than date limits. This returned a larger body of work. The terms 'squalor' and 'unsanitary or insanitary' were also used to attempt to locate literature that focused on lack of care of one's environment, but may not have mentioned self-neglect. This searching process, and the number of publications identified by these searches, is in Table 2:

**Table 2. Results of electronic database supplementary searches**

	Results from Social Care Online (since 2009)	Results from Psycinfo (since 2009)	Results from ASSIA (since 2009)
Self-neglect AND workforce	0	0	0
Self-neglect AND training	1	4	3
Self-neglect	22	61	8
Squalor	6	14	1
Unsanitary OR insanitary	0	7	1

Once duplicates and papers that did not focus significantly on self-neglect were removed, 34 additional studies remained. These were added to the 160 identified in the previous review, resulting in a total of 194 studies on self-neglect.

Of all these, none met the inclusion criteria or directly addressed this present study's research questions, within the UK context:

- What is the range of social care workforce groups involved with self-neglect?
- What is the available evidence on the nature and extent of self-neglect cases coming to the notice of social care agencies?
- What are perceived workforce development needs in different agency contexts, and with the different manifestations of self-neglect?
- What is the available evidence on the costs of unmet need in self-neglect?

It was apparent that self-neglect research, particularly outside North America, has been bedevilled by a lack of consistent definitions and the virtual absence – until recently – of ongoing monitoring of prevalence and outcomes data. This has resulted in the current lack of literature examining relevant workforce issues, the demands placed on social care agencies, and the costs involved. As a consequence, the decision was made to broaden the inclusion criteria to include:

- studies set in the health services, and
- studies from outside the UK.

While these did not directly focus on the research questions and setting of interest to this evidence review, they did at least allow the research team to draw on some discussion of research into the extent of self-neglect cases. The main body of studies that dealt empirically with the challenges of practice in self-neglect were qualitative in

nature or examined case files; hence both qualitative and quantitative methods were included in discussion of what evidence for recommendations for practice emerges from the literature.

## Appendix 2: Topic list for discussions

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1. What kind/level of work is being done in your organisation/team with people who self-neglect?
2. Do we have any idea of the number of cases being worked with, or the proportion of adult social care work/your work that involves self-neglect?
3. Which workforce groups are primarily involved?
4. What are the training and workforce developments needs of practitioners and managers working in situations of self-neglect? Examples might be:
  - knowledge
  - skills
  - supervision
  - support (e.g., what do we know about the impact of self-neglect work on staff?)
5. Have any initiatives have been undertaken in workforce development for self-neglect in your organisation? Examples might be:
  - training
  - support/supervision arrangements
  - other ways of facilitating people's knowledge and confidence with self-neglect work
  - broader systemic approaches such as competence/role mapping.
6. What has been learnt from the initiatives? Is there any available data on monitoring the benefits and costs of any initiatives taken?
7. Do we have any knowledge of the potential costs of carrying out work in self-neglect, and of the longer-term costs when intervention is refused?
8. Do we have any knowledge of the cost effectiveness of self-neglect workforce development initiatives?
9. What kinds of future training and workforce development initiatives might be considered desirable/priorities?
10. How can Skills for Care best support these? What should be their role as a sector skills council?

## Appendix 3: Findings on workforce development needs for self-neglect practice

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This appendix presents in tabular form the findings from the interviews and focus groups on workforce development needs. Whilst the findings narrative is embedded in the report, the table below may assist in providing a map of the analysis.

There are two main findings categories:

- workforce development
- workplace development

### A. Workforce development

Knowledge about self-neglect	<p>definitions, symptoms, causes, risks</p> <p>complexity of factors</p> <p>OCD and other conditions associated</p> <p>impact of capacity</p> <p>impact of loss and bereavement</p> <p>philosophical and ethical background (autonomy)</p>
Knowledge about interventions	<p>assessment</p> <p>legislation</p> <p>psychosocial interventions</p> <p>brief and solution-focused therapies</p> <p>harm-reduction approaches</p> <p>positive risk-taking</p> <p>relationship-based practice</p> <p>counselling</p> <p>long term support strategies</p> <p>knowledge of systems: practical services available – who can do what from the interagency network; demand for procedures and guidance that are specific to self-neglect</p>
Skills and know-how	<p>assessing capacity</p> <p>joining and engaging</p> <p>working with resistance and low motivation</p> <p>patience</p> <p>person-centred communication</p> <p>negotiation skills – creating change through relationship</p> <p>decision-making that balances conflicting imperatives</p>
Professional	<p>ability to follow own pace or style</p>

confidence	<p>exercise freedom and creativity of approach</p> <p>move away from proceduralised practice</p> <p>ability to frame person-centred outcomes</p>
Professional values and perspectives	<p>self-awareness</p> <p>respect for personhood</p> <p>non-judgementalism, tolerance</p> <p>ability to tolerate uncertainty and risk</p> <p>constructive use of power</p>
Supervision at two levels	<p>(a) Support</p> <p>personal impact of the work</p> <p>frustration</p> <p>emotional burden</p> <p>preventing burnout</p> <p>building emotional resilience</p> <p>(b) Practice development</p> <p>reflecting on experience</p> <p>discussing approaches</p> <p>use of peer supervision, practice development forums</p> <p>legal advice</p> <p>‘proper social work’</p>
Partnership working	<p>recognition of diverse contributions</p> <p>negotiation</p> <p>convening systems</p>
Learning culture	<p>organisation, team, individual</p> <p>use of feedback from service users and carers</p> <p>learning from practice embedded in workforce development and training planning</p> <p>resources to support own research and development</p> <p>briefings on outcomes of reviews – management, SCRs, complaints</p> <p>time to make use of them</p>
Importance of targetting workforce development initiatives at the appropriate levels in the organisation – matching to job role - Front line, Managers	
Importance of multiagency training – learning to do things together	
Importance of longitudinal approaches – qualifying, newly qualified, CPD	

## B. Workplace development

Service culture	<p>(a) review of the extent to which services are geared to independence:  a need for different pathways for complex clients who do not meet the “2-years pathway to independence” requirements  renegotiation of what we mean by outcomes  review of commissioning practices with voluntary organisations</p> <p>(b) a different approach that gives time and space for long, slow-burn involvement  doesn't rush things or make barriers from entry criteria that people who self-neglect aren't going to meet  no worry if it looks like nothing's being done  permits keeping in touch in a casual but purposeful way  the possibility of 6-monthly review even if cases are 'dormant'</p> <p>(c) a system for cases that fall below the eligibility thresholds for adult social care and for whom the usual response of 'signposting' to other services is not appropriate</p>
Risk management and decision-making structures and processes	<p>(a) the need for a decision-making hub or panel that can share information, give a joined-up and holistic risk view, consider options, decide who will do what, enable early intervention, co-ordinate responses</p> <p>(b) ideally this would be interagency “we should all collectively own it” (like MARAC)</p>

## Appendix 4: A training strategy for self-neglect practice

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### **Level 1 – Self-neglect – basic awareness**

**Overview:** This booklet will help to provide an understanding of what is self-neglect and the reporting procedures contained in the Self Neglect Procedures. The booklet is aimed at anyone who may come into contact with an adult who is putting themselves at risk of harm through self-neglect, including Police, Ambulance Service and Fire and Rescue Services.

By reading and completing this booklet you will be able to:

- describe key definitions and signs of self-neglect
- know about obligations to report under the self-neglect procedures
- know when and how to report self-neglect
- recognise how safeguarding and the mental capacity relate to self-neglect.

### **Level 2 – Self-neglect - frontline staff**

**Who should attend:** Those who regularly support or have sustained contact with those who are putting themselves at risk of harm through self-neglecting including, Adult Social Care staff, Care Support workers, Mental Health practitioners, Housing Officers, Community Nurses, GPs, Community Support Workers, Environmental Health Officers, Voluntary sector (including animal welfare such as RSPCA employees).

**Overview:** In the self-neglect procedures, self-neglect is defined as ‘the inability (intentional or non-intentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the self-neglecters and perhaps even to their community.’

(Gibbons, S. 2006. ‘Primary care assessment of older people with self-care challenges.’ *Journal of Nurse Practitioners*, 323-328.)

This course will support frontline staff to work with adults who are believed to be self-neglecting, and putting themselves at risk of harm. The course introduces the Self Neglect Procedures and the multi-agency approach to supporting people who self-neglect. Participants will have an opportunity to consider case studies and to meet with

colleagues from other disciplines to help develop an understanding of different approaches to working with this complex issue.

### **Learning objectives**

By the end of this course participants will be able to:

- describe key definitions and signs of self-neglect
- explain when and how to report, and also record concerns of self-neglect
- describe key attitudes and behaviours when working with a person who is at risk of harm through self-neglect
- have knowledge and understanding of factors potentially relevant for individuals who self-neglect, and for working positively with them
- explain the multi-agency approach and their role
- recognise and consider approaches to help their emotional and psychological wellbeing when supporting a person who is putting them at risk of harm through self-neglect.

### **Level 3 – Self-neglect – planning and coordinating successful interventions**

**Who should attend:** Those who are supporting and involved in decision-making and assessments for people who are believed to be self-neglecting and at risk of harm, including Senior Social Workers, Assessment Team Managers, Housing Managers, GPs, Health Professionals, Primary and Community Health Care, and those working in Mental Health Services.

**Overview:** In the Self Neglect Procedures, self-neglect is defined as ‘the inability (intentional or non-intentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the self-neglecters and perhaps even to their community.’ (Gibbons, S. 2006).

The procedure sets out a clear multi-agency approach to working with people who self-neglect and identifies lead agencies and responsibilities for a planned response. This course is aimed at those involved in the planning of any response.

### **Learning Objectives**

By the end of this course participants will be able to:

- describe key definitions and signs of self-neglect
- have considered appropriate interventions for identified risks
- explain roles and responsibilities under self-neglect procedures
- explain the relevance of mental capacity to working with people who self-neglect and discuss legal interventions, limitations and ethical issues
- describe helpful approaches and interventions

- review processes and actions in relation to improvements or deteriorations in cases of self-neglect, including recognising when to instigate a multi-agency planning meeting.

**Level 4 – Self-neglect – strategic level engagement**

This is under development.

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