

Self-neglect policy and practice: early research evidence about good practice



This research set out to identify what could be learned about current policy and practice in self-neglect, experienced as a highly challenging aspect of contemporary adult social care.

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Executive summary

1. Introduction

This research, commissioned by the Department of Health (DH), set out to identify what could be learned about current policy and practice in self-neglect, experienced as a highly challenging aspect of contemporary adult social care. A national (England) survey investigated current strategic and policy initiatives, with responses from 53 out of 152 local authorities (34.9 per cent). A series of in-depth interviews undertaken with 20 managers, 42 practitioners and 29 people who use services across 10 authorities identified approaches that have produced positive outcomes from the perspectives of those involved.

2. The national picture

From the survey responses, the majority of local authorities and their partner agencies in safeguarding do not routinely collect data on the prevalence of self-neglect, although other data could sometimes provide useful indicators. As a consequence, estimates of the volume of self-neglect work being undertaken in localities varied widely. Just over half the authorities responded that they had defined or profiled examples of self-neglect in guidance or protocols; two-thirds had provided guidance to staff, but just a quarter had provided training on self-neglect, although it could be touched on in other training such as that on safeguarding, or mental capacity.

The aspects of self-neglect work experienced as the most challenging related to situations of very high risk in which someone with mental capacity refused services. Such situations raised ethical dilemmas in the balance to be struck between respecting autonomy and fulfilling a duty of care. Different agencies sometimes had different expectations of the thresholds for intervention; scrutiny of legal options was deemed vital. Further challenges were identifying where lead responsibility for self-neglect lies, who should be involved, and whether it resides within the remit of adult safeguarding or elsewhere. Common referral routes were into adult social care teams and/or through safeguarding alerts; joint work was often undertaken with housing or environmental health. A small number of agencies referred to the role of a multi-agency discussion panel in facilitating shared risk assessment and management, shared ownership and coordinated interdisciplinary involvement. There was recognition that care management systems did not always allow the time and continuity of involvement that could facilitate relationship-based practice.

In just over a quarter of authorities self-neglect had featured in a serious case review (SCR), and the findings had led to changes in policy or practice, with a focus on referral routes, multi-disciplinary engagement, shared risk management and the provision of strategic overview by the Local Safeguarding Adults Board (LSAB).

3. The perspectives of managers, practitioners and people who use services

A number of key themes emerged from the in-depth interviews.

The importance of creating a strategic and operational infrastructure for self-neglect practice

Ownership: Strategic development of policies, protocols and practice tools to meet the challenges posed by self-neglect needs an organisational home. Managers in particular emphasised the importance of inter-agency governance, whether this structure and ownership were provided through the LSAB or some inter-agency parallel mechanism. Examples of both models were given, along with hybrid models in which separate policies and procedures for self-neglect were strategically linked to the LSAB.

Training, supervision and support: Where some strategic infrastructure was in place, multi-agency training in self-neglect was sometimes becoming available, although from the practitioners' perspective it was not widespread, and practitioners were more likely to have encountered self-neglect tangentially in other training, or to have transferred their learning from other contexts. Where training on specific aspects of self-neglect had been experienced, it had sometimes had a powerful influence on how practitioners approached their practice. The personal, emotional impact for practitioners of working with self-neglect was also apparent; engaging with sadness and despair, and the poignancy of people's attempts to deal with such feelings, is deeply moving, and feeling helpless yet responsible is a very uncomfortable place to be. Such experiences indicated the need for robust supervision and support mechanisms to be in place.

Referrals and data collection: Referral pathways were another aspect of creating an infrastructure that would enable effective responses to be made, whether these were to safeguarding, adult social care, or multi-disciplinary teams. Managers were particularly keen to develop ways of capturing data on self-neglect, while recognising the challenges arising of defining such a complex concept, agreeing thresholds and securing participation from the likely range of agencies involved.

Approaches to practice that facilitate outcomes perceived as positive by those involved

Relationship: The most constant theme that emerged from the interviews with practitioners and people who use services interviews was the importance of relationship in securing engagement and achieving interventions that could make a difference. Such relationships take time to build, and continuity of involvement over a long period of time may be needed to build the trust that can achieve tangible outcomes. The people who use services emphasised the practitioner's ability to show humanity, be reliable, show empathy and patience, be honest and work at the individual's own pace as important components of helping. There was some consensus between practitioners and managers that care management models that restrict the time and focus of the practitioner did not provide the structure in which such work can be done, and many examples were given of ways in which workflow was adapted to facilitate ongoing involvement.

Finding the person: Equally important were approaches that enable the practitioner to explore and understand the individual's life history, and its possible connections

with current patterns of self-neglect. Early experience, trauma, loss and relationship all figured strongly in the service users' stories, and in the narratives of practitioners as they recounted how they had constructed bespoke interventions that responded to and took account of each person's personal life experience, networks, relationships and motivations. Equally powerful were the ways in which practitioners recognised the emotional component of the service users' current experience of their circumstances, working with the fear, anxiety, embarrassment and shame that were sometimes present. Equally, people who use services emphasised their own resilience and determination, and valued practitioners who recognised and worked with those qualities.

Legal literacy: Mental capacity frequently featured in practitioners' narratives, and was also recognised by managers as a key determinant of what intervention could and should take place. Knowledge of legal requirements was therefore an essential underpinning to practice. In many cases capacity assessments were routinely being evaluated and updated, with approaches that were fine-tuned and, where necessary, multi-disciplinary, although some respondents raised concerns about how thorough and confident practice was in this respect. The interface between different forms of legislation required skills in navigating and weighing different options, and expert advice in complex cases was vital.

Creative interventions: No model intervention emerged, the key themes being flexibility (to fit individual circumstances), negotiation (of what was within the service user's zone of tolerance), balance (between competing imperatives such as risk and safety) and proportionality (to moderate rather than seek to eradicate risk, in a way that preserved respect for autonomy). Engagement was often created through the provision of practical items – fridges, heaters – or support with benefits, which could be accepted more easily, building a relationship that would then enable attention to be turned to care of the domestic environment or (often the last to be agreed) personal care. Where intervention to clear or clean property was necessary, securing the individual's engagement in deciding what should stay and what should go often achieved a more consensual outcome. Recognition was given to the attachment that people often had to their possessions or surroundings, and the need therefore to replace what was being given up with forward-looking intervention focusing on lifestyle, companionship and activities. Coercive interventions were also sometimes necessary, and used, although the perspectives of people who use services showed that directive approaches were deeply unwelcome. Practitioners recognised that the cost was high in human terms, and proceeded only with reluctance, when a basic level of existence was threatened, or risks to others were extreme. But there were examples of such interventions that, with honest but empathic engagement, and as part of an ongoing relationship and care plan, produced positive change.

Multi-agency working: Convening practitioners who could contribute a range of disciplinary perspectives to self-neglect proved to be a powerful tool in practice. Collaboration was often highly effective on the ground, with examples of strong engagement between adult social care, medical and health practitioners, the police, housing, environmental health, voluntary organisations and many others to develop shared understandings of a given situation, which could then inform the interventions selected as priorities. Case conferences, team discussions, multi-agency risk panels and other ways of convening partners were generally experienced as positive in confirming a sense of direction in an individual case, and in agreeing where the most appropriate focus should be placed, and by which agency.

4. Conclusion

It is clear that self-neglect policy and practice is as complex and as varied as self-neglect itself. From the experiences of those who have contributed to this research – whether as people who use services, practitioners or managers – it seems that effective practice combines three key sets of factors:

- *Knowing*, in the sense of understanding the person, their history, the significance of their self-neglect, along with all the knowledge resources that underpin professional practice.
- *Being*, in the sense of showing personal and professional qualities of respect, empathy, honesty, reliability, and care, being present, staying alongside, keeping company, being human.
- *Doing*, in the sense of balancing hands-on and hands-off approaches, seeking the tiny element of latitude for agreement, doing things that will make a small difference while negotiating for the bigger things, and deciding with others when intervention becomes a requirement.

The importance of creating a strategic inter-agency infrastructure to facilitate such practice cannot be over-estimated; referral pathways, discussion mechanisms, flexibility in work allocation practices, training and support all have a key role to play, as does an ethos of shared ownership between the agencies whose interventions can make a difference. That this is difficult is well established; that it can be done is now evidenced by this research.

1. Introduction

1.1 Background to the research

Self-neglect has emerged as a significant challenge to practitioners and policy makers across a range of agencies. A previous scoping study commissioned by the Department of Health (DH) (Braye *et al*, 2011a) revealed that the term covers a wide range of behaviours – such as hoarding, living in squalor or neglecting self-care and hygiene – that in different ways manifest unwillingness or inability to care for oneself and/or one's environment. The scoping study identified a range of research studies, predominantly undertaken outside the UK, which have sought to isolate biological, behavioural and social factors associated with self-neglect, but no overarching explanatory model has emerged, and self-neglect may be said at best to encompass a complex and individualised interplay between mental, physical, social and environmental factors. More significantly for the purposes of the present study, while certain recommendations recur regularly in the literature – notably the importance of sensitive and comprehensive assessment, attention and persistence in building up trustful relationships, and good legal literacy – robust evidence on effective interventions is lacking, particularly within the English context.

Capacity is well understood as a significant factor in determining intervention options but is complex, and is experienced as challenging to assess in this context. Where mental capacity is lacking, professional networks are clear about the requirement to act in the individual's best interests, but do not always agree on how to intervene. Where capacity is present, there is strong professional commitment to supporting an individual's autonomy in choosing their own way of life; however, the perceived professional commitment both to promote dignity and exercise a duty of care means that competing imperatives drive professional goals. This, coupled with an experienced complexity of legal rules involving human rights, information sharing, protection and personalisation, may produce strain within inter-professional practice.

Self-neglect occupies an ambivalent position in relation to adult safeguarding; many Local Safeguarding Adults Boards (LSABs) explicitly exclude self-neglect from the remit of their safeguarding procedures – a position consistent with *No Secrets* guidance (DH, 2000) which focuses on harm to vulnerable adults caused by a third party. Yet the perceived need for inter-agency discussion of serious self-neglect cases gives rise to the use of safeguarding communication and information-sharing systems, or, in some locations, to the creation of parallel systems for the management of risk.

A second study conducted by the same authors (Braye *et al*, 2013) sought to identify the range of staff engaged with self-neglect work and their perceived workforce development needs. It identified that relevant literature was sparse, but it also captured the recommendations of serious case review (SCR) and Ombudsman reports for improving practice with adults who self-neglect (Braye *et al*, in press a, b). These include an emphasis on the involvement of senior managers in complex cases, a multi-agency approach to assessment and risk management, and thorough assessment and review of an individual's mental capacity, as well as training on effective ways of working with adults who self-neglect.

The study also found that quantifying the volume of self-neglect work by local authorities and their partner agencies was challenging, complicated by the lack of shared definition and the variety of referral pathways. It uncovered individualised approaches to self-neglect work by a diverse range of agencies. Practitioners and managers reported a number of challenges in this field of work, including how to define self-neglect and where best to locate it strategically and operationally. The work was perceived as complex and high risk, complicated by divergent agency thresholds for triggering concern and involvement, competing value perspectives, and unclear legal frameworks and care management workflow arrangements. What practitioners and managers emphasised was their need for knowledge about, and skills for, effective interventions with adults who self-neglect, located within organisational structures that offered space and time for building relationships, opportunities for reflective supervision, and arrangements to facilitate creative practice and shared risk management and decision making.

1.2 Purpose of the research

The two scoping studies summarised above identified the substantial challenges self-neglect poses to adult social care policy and practice. Reaction to the dissemination of the published research reports has been one of intense interest, triggering discussions that have indicated the scope of the challenges being faced. The pitfalls within policy and practice evident from SCRs (Braye *et al*, 2013, in press a, b) help to understand practitioners' and managers' interest in developing a knowledge and skills base for working with adults who self-neglect. Practitioners, managers and policy makers are seeking clear guidance to back up the initiatives being taken, or to cast light on effective ways of working in the English legal and policy context.

While the challenges are clear, there is less evidence showing the ways in which practitioners work creatively to manage risks from self-neglect in the context of an empowerment approach to practice. Pockets of effective policy and practice are emerging; collaboration between adult social care and housing, and the active involvement of fire services in prevention and risk management, are examples. Yet evidence of successful outcomes from policy and practice approaches employed is lacking, in part because the research to find it has not yet been done. The present research report therefore seeks to fill this gap.

1.3 Towards an evidence base for policy and practice

This is a large-scale study that provides a mix of breadth and depth of enquiry, and both quantitative and qualitative data. A national questionnaire survey of English local authorities investigated the extent of the challenge posed by self-neglect work and current responses to it. It was complemented by an in-depth investigation of practice, undertaken in a small number of authorities, which specifically identified approaches that have been developed and experienced as constructive in engaging with people who self-neglect. This provided findings from practitioner and managerial accounts of inter-agency policies and approaches that have produced positive outcomes in self-neglect work, and from the perspectives of people who use services on professional interventions and the impact they have made on their lives. The in-depth interviews enabled the researchers to identify:

- a range of case accounts from practitioners, managers and people who use services, which demonstrate constructive practice in self-neglect, as well as the challenges encountered;
- a range of policy and procedural developments that enable practitioners and their managers to discuss the challenges posed by cases of adults who self-neglect; and
- common features within those accounts that allow key indicators of good policy and practice to emerge.

In some respects, this approach takes the reverse of the SCR approach seeking to identify what can be learned from good outcomes in specific cases.

Specifically this report includes, in the order in which they appear:

- This introduction, giving the background to the research.
- A short overview of the methods used in the research.
- Results from a national (England) survey of the volume, nature and outcomes of cases involving adults who self-neglect currently being managed by local authorities, and the protocols and procedures being used for managing these cases.
- The perspectives of managers interviewed, on the strategic and operational aspects of self-neglect work and the policy and procedural environment in which it is conducted; the perspectives of service users interviewed, on their experience of self-neglect and of professional interventions.
- The perspectives of practitioners interviewed, on their approaches to self-neglect practice.
- A concluding commentary.

The practice interventions described in the interviews vary widely in nature, but common themes and patterns emerge consistently across the accounts. They offer a rich and detailed account of the interactions between key players. The opportunity to understand, from their own account, the perspectives of people who use services on what has best supported them makes a key contribution to understanding of good practice in this context, given the paucity of existing research that has captured such perspectives.

The intention of the research project was to build an evidence base and knowledge base to inform policy development and practice. This report draws on accounts of a range of approaches found to be effective in working with adults who self-neglect and the outcomes they had. Short case vignettes illustrate the factors that make for effective intervention and outcomes. The quantitative data on the number of cases being managed, in the absence of national data, provides an important picture on the nature of work being conducted in self-neglect. The analysis of inter-agency policy and practice across the broad range of localities enables common themes of effective inter-agency work in self-neglect to emerge, and provides the basis for future guidance.

2. Method

A national survey was carried out of the volume, nature and outcomes of self-neglect cases. This sought information on self-neglect practice as a background against which to situate practice investigated in the localities selected for interview. In parallel with the survey, semi-structured interviews were conducted with safeguarding and social care managers, practitioners and people who use services, in order to gather differing perspectives on what contributes to effective work in addressing self-neglect. An important aim of the research was to gather stories of individual cases, to learn about what had worked well and what had been less effective in those situations. Another key aim was to identify what procedural approaches and protocols within and between agencies facilitated successful work by practitioners.

2.1 Survey

The survey questionnaire (available both online and as hard copy) was disseminated to all local authorities in England through the Association of Directors of Adult Social Services (ADASS). The survey contained questions about: data collection on self-neglect; volume of self-neglect cases; definitions, guidance and protocols regarding self-neglect; key challenges; training; processes and pathways; and any key lessons learned (see Appendix 1 for full details). The purpose of the survey was to obtain a broader picture of self-neglect practice than was possible at the selected sites alone, as well as to identify any further localities taking innovative approaches that might merit follow-up interviews in their own right.

The data gathered from the survey were expressed as basic descriptive statistics. Few authorities reported recording detailed figures on self-neglect as a distinct category, so data that would have enabled more advanced statistical analysis proved to be lacking. Brief qualitative data was also gathered in response to the survey.

2.2 Interviews

The semi-structured interviews each followed one of three topic lists (see Appendix 2). Interviews with managers focused on: core objectives and future priorities; agency definitions; policies and guidance; data collection; inter-agency working; training; and key challenges, all in relation to self-neglect. Interviews with practitioners focused on: the level of experience and training they brought to self-neglect work; their accounts of self-neglect cases with which they had worked; agency and inter-agency arrangements that supported them in this; the impact it had on them; and access to supervision and support. Interviews with people who use services focused on: their experience of self-neglect; how they had become involved with services and their feelings at different stages of that involvement; the nature of the support provided; the outcomes; and whether anything should have been done differently by services.

Purposive sampling was used to select seven local authorities in which to conduct the interviews. Previous studies (Braye *et al*, 2011a, b, 2013) had enabled the research team to build up a network of contacts among local authorities that were actively addressing the challenges of self-neglect. Using this knowledge of the field, authorities were selected in which examples of good practice might be identified. Since this study focused on positive outcomes of intervention, a broader

representation of practice outcomes was not sampled. However, a mix of rural and urban authorities was sought from different regions of England. This was partly because of the possibility that self-neglect in areas of higher-density housing might affect others more significantly than elsewhere and that this might influence service responses, and partly in order to ensure that the applicability of our findings would be as wide as possible. Four additional authorities reporting potentially interesting work on self-neglect were identified by the survey, and interviews were arranged at three of these; interviews at the fourth proved impossible to implement in a timely fashion. The findings are thus drawn from interviews held in 10 different authorities.

Contact was initially made with the Director of Adult Social Services in each authority, who then identified relevant managers who could in turn identify practitioners with an interest in, and/or recent cases involving, self-neglect. Either before or during the interviews, practitioners were asked if they either had on their caseload, or knew of, people who use services who might be willing to speak about their experiences. Where they had capacity to consent to participate in the research, they were invited for interview. Throughout this chain sampling process, the research team sought to avoid being prescriptive about a definition of self-neglect,¹ stating only that it 'covers a range of behaviour that in different ways shows unwillingness or inability to care for oneself, and/or for one's home,' and mentioning the examples of 'hoarding, lack of personal care and levels of cleanliness or infestation that pose severe risks to health and wellbeing' (see the Information Sheets in Appendix 3). This allowed a certain degree of scope for services and people who use services to interpret it according to local policy or personal experience.

Twenty interviews were conducted with managers in a range of roles that included strategic, operational and specialist responsibilities. Interviews also took place with 42 practitioners, mainly social workers and social care staff. Through the practitioners, the researchers were put in touch with people who use services and carers, 29 of whom agreed to participate in interviews about their experience of self-neglect. Although the study was not seeking carers' perspectives, two who particularly wished to participate were interviewed. The accounts of people who use services were triangulated with those of the practitioners who had worked with them, but many were contacted indirectly; for example, practitioners might have facilitated contact with a hoarding group or other specialist service, from which interviewees came forward. In these cases, the practitioner would often not have worked directly with the service user, and it was not possible to gather both perspectives. In total, eight 'matched pairs' of people who use services/practitioners were included within the study sample; full triangulation could not be achieved for the others.

Where the interviewee gave permission, interviews were recorded and transcribed. In some cases, permission for recording was withheld, and so written notes were taken instead. Data were analysed using the framework analysis method (Ritchie and Lewis, 2003). This took place in three stages:

1. An initial conceptual framework was developed by reading and re-reading a sample of the transcriptions and developing a preliminary index of themes, then grouping these into more general categories. Since the interviews were already partially structured by prepared topic lists, the framework reflected these to a degree,

¹ This is in keeping with the lack of an existing legal definition and the flexibility of designation apparent in the research literature (Band-Winterstein *et al*, 2012, pp 109–10; see also Braye *et al*, 2011c).

although it also took account of how the interviews had then unfolded. Once developed, it consisted of 39 themes grouped under seven main headings:

- Service-level approaches
- Practitioner experience of self-neglect
- Service user life history of possible relevance to self-neglect
- Nature of self-neglect
- Actual response from services and others
- Counterfactual or potential outcomes (how things might have been done or happened differently)
- Other key issues not considered above.

The data from all transcriptions were labelled by applying relevant themes from among the 39 in the index, to indicate the topic(s) of individual passages of the interviews.

2. All the data were then grouped by theme into an analytic matrix, allowing all material coming under each theme to be considered together. This enabled a further thematic analysis process, focusing this time not just on the topic relevance of what interviewees had said (as at the indexing stage), but on newly identified themes emerging from the content seen as a whole, rather than from the initial framework.

3. The themes that emerged at this stage were identified, summarised and then brought together into higher-order categorisations that encompassed them within a smaller number of overarching classifications. It is these that have been used to inform the analysis presented in this report.

2.3 Ethics

Ethical permission was sought and received from the national Social Care Research Ethics Committee (Ref. 13/IEC08/0013). Further approval was later sought and obtained for a non-substantial amendment to increase the number of authorities included, after additional authorities of interest were identified by the survey. The Research Group of the ADASS scrutinised and approved the research (approval reference number Rg13-014), and permission to contact managers, practitioners, people who use services and carers was also sought from senior management within each individual local authority before undertaking interviews.

The participation in the study of people who use services and carers was mediated through practitioners; while this limited involvement to those pre-selected by professional staff, it ensured an informed assessment of the capacity of individuals to consent to take part, and an informed judgement about the risks of distress that might result from doing so. Full information was presented to service users and carers before the interviews took place (see Appendix 3), and interviews only proceeded where they were judged to have capacity and to have fully understood the implications of participation.

3. National survey of policies and practice

3.1 Response rate

A total of 55 surveys was completed. Two were multiple responses from the same local authorities, in other words, two sets of doubles. However, these two additional surveys were completed by different agencies and each provided unique information about self-neglect. The qualitative information provided in these survey responses has therefore been included in the results alongside the others, while the duplicate quantitative responses were not counted where they might skew the statistics (the one exception to this approach is shown in Table 3). The responses thus provide data from 53 local authorities, from a possible 152, giving a response rate of 34.9 per cent. Tendency for elements of the data to be self-selecting, and therefore bias the findings, is a potential issue. It is possible that localities that have not as yet given much consideration to self-neglect would be less likely to reply, as managers there may have felt that they would have had little to contribute by responding to the survey. If so, the overall picture of work being done on self-neglect may not be significantly greater than is suggested by the survey findings. An alternative possibility is that responses were from more highly functioning teams, and that those who were more overstretched were less likely to reply. This may also have influenced the findings. A further possible limitation of the methodology is its reliance on the respondent having adequate knowledge to answer the questions fully and reliably. However, the survey did inquire into this by asking how confident the respondent was in their answers. The survey was also directed at safeguarding leads, those most likely to know of anything that had been actively pursued on self-neglect.

Comparisons of local authorities who responded and who did not respond were carried out using Chi-square analysis by local authority region ($\chi^2 = 4.14$, $df=8$, $p=0.85$) and type ($\chi^2 = 0.66$, $df=3$, $p=0.88$), showing no significant differences. This suggests that the responding local authorities are broadly representative of all local authorities by these characteristics.

3.2 Demographics

Surveys were returned from all regions, with the largest proportion from the London boroughs (22.6 per cent) and the smallest from the North East (5.7 per cent) (see Table 1). With regard to type of authority, the largest proportion of surveys was received from unitary authorities (34 per cent), with the remainder distributed fairly evenly between metropolitan boroughs (22.6 per cent), non-metropolitan counties (20.8 per cent) and London borough councils (22.6 per cent) (see Table 2).

Table 1: Frequencies and percentages of responses per local authority region

Local authority region	Number of responses	% of responses
North East	3	5.7
East Midlands	4	7.5
London	12	22.6
Eastern	5	9.4
North West	7	13.2
South East	5	9.4
South West	8	15.1
West Midlands	4	7.5
Yorkshire & the Humber	5	9.4
Total	53	100

Table 2: Frequencies and percentages of responses per local authority type

Local authority type	Number of responses	% of responses
Unitary authority	18	34.0
Non-metropolitan county	11	20.8
Metropolitan borough	12	22.6
London borough council	12	22.6
Total	53	100

Of the 55 respondents, 4 (7.3 per cent) were directors/assistant directors, 13 (23.6 per cent) heads or acting heads of safeguarding, 27 (49.1 per cent) managers/leads in safeguarding or service provision, 4 (7.3 per cent) safeguarding coordinators and 5 (9.1 per cent) officers in safeguarding. Of the two remaining, one respondent had a senior data and performance role and another did not answer this question (see Table 3).

Table 3: Frequencies and percentages of roles of respondents

Role	Number of respondents	% of respondents
Director/assistant director	4	7.3
Head/acting head of safeguarding	13	23.6
Manager (safeguarding/service provision)	27	49.1
Safeguarding coordinator	4	7.3
Officers in safeguarding	5	9.1
Other	2	3.6
Total	55	100

3.3 Volume of self-neglect cases

3.3.1 Are data collected on self-neglect?

Respondents were asked whether their authority routinely collected data on self-neglect. The majority, 32 (60.4 per cent) authorities, said they do not routinely collect data on self-neglect. Only five (9.4 per cent) authorities routinely collect this data, and a further 16 (30.2 per cent) collect related data that may be useful (see Table 4).

Table 4: Frequencies and percentages of responses regarding the routine collection of data on self-neglect

Question 4 Do you routinely collect data on self- neglect?	Response	Number of responses	Response %
	No	32	60.4
	Yes	5	9.4
	Not specifically, but we do collect related data which may be useful	16	30.2
	Total	53	100

3.3.2 What kind of data?

Responses from those who said that they did routinely collect data included reference to details of the person coupled with assessment and outcome, agencies involved, review dates and/or risk management plan. One agency routinely recorded self-neglect as a type of abuse where this was identified at referral, but other forms of abuse would be recorded at the same time if mentioned (and could have had a confounding effect on the quantification of self-neglect). Another respondent noted that self-neglect cases were identified through safeguarding processes in severe cases where the Mental Capacity Act 2005 had been used to establish that an individual lacked capacity in decision making regarding their own care and/or their environment.

When responses of 'no' and 'not specifically' were given, 15 respondents referred to related data that was collected, such as biographical or care-specific data, including details of the individual, assessment of need, risk assessments and plans, and outcomes. This could then enable data collection on the number of referrals and types of follow-on action. Some respondents noted that their authorities either only collected data required by the Safeguarding Adults Return, or had stopped collecting self-neglect data under safeguarding headings because it caused problems for this form of national reporting. Nonetheless, within safeguarding referrals about abuse, it could be possible to find reference to self-neglect.

Other local authorities were using referral forms that included boxes to indicate the nature of vulnerability. One option here was neglect. However, analysis of individual case notes and assessment records would be necessary to indicate whether this was self-neglect and/or neglect by others.

"We do not use the term 'self-neglect' or similar but there are dispersed questions throughout the community care assessment that, if pulled together, could be a useful indicator if we wanted to use that as a concept/tool. Our approach is to identify risks and these are broken down into risks to health, risks of fire etc. These

may build a picture we could term self-neglect but at the moment we do not take this approach. Our colleagues in Children's Services recently adopted a neglect tool and assessed some cases retrospectively and found that this would have led to different outcomes, so it is something in Adult Services we would be interested in. General assessment for community care services covers questions about the person's ability to do house work and look after themselves. There is an 'other information' box. The dispersed questions, free text and inconsistent way of recording does not make reporting feasible or robust as 'self-neglect.'"

Thus, data on self-neglect might not be collected systematically but could emerge, or be extracted from, information contained within referrals to adult social care or safeguarding, for example, from fire or ambulance services and the police, assessment, planning and review processes, MARAC (Multi-Agency Risk Assessment Conference) and MAPPA (multi-agency public protection arrangements) systems, and referrals to 'chaotic lifestyles' case conferences. However, collating this data would not necessarily be a quick or straightforward task.

One respondent commented that data on self-neglect was not captured centrally, but that social care teams logged referrals of people who self-neglect and drew up an intervention plan within a care management approach. This respondent added that intensive social work support was provided to those who were regarded as putting their health at risk because of their living conditions or rejection of personal care support, again with intervention plans designed to secure a satisfactory outcome. Another recorded that data was collected by a voluntary organisation commissioned by the local authority to provide specific services:

"Age UK collect some data on referrals that go through their 'Linking People' service. They have reported that in 2010-11 they recorded 2 cases of self-neglect, in 2012-13 this rose significantly to 15 and by 12th July 2013 they have recorded 8 – indicating referrals continue to increase."

The emphasis on extracting information about individuals from records rather than systematically collecting self-neglect data was reinforced by four respondents, who commented specifically on individual data. This could involve local intelligence on particular individuals or information not easily accessible but that could be collated manually from individual records. Echoing the reference above to data held by social care teams, one respondent indicated that cases of self-neglect were dealt with on a case-by-case basis, perhaps through a housing route when a tenancy was at risk, with cross-service liaison with adult social care when necessary.

Two respondents referred to data collected under a specific policy framework. In both cases the policy covered high-risk situations, such as where serious injury or death was possible, where an individual was not engaging with services.

One respondent referred to mental health records held by multi-agency teams that enabled recording within needs assessment and risk assessments of whether an individual was at risk of neglect. This could refer to self-neglect. In other services in this local authority area, data on self-neglect was not routinely recorded. Similarly, three respondents referred to hoarding and self-neglect with fire brigade intervention.

Data was specifically collected on the number of people who were hoarders and on the number and origin of referrals made for fire safety checks or to adult social care.

One respondent referred to a survey of carers, carried out every two years, which asked whether they experienced difficulties looking after themselves well enough or whether they were neglecting themselves. In the last survey, 56 carers (18.5 per cent) had indicated that they felt that they were neglecting themselves. Finally, one respondent indicated that self-neglect was potentially a very broad term, potentially including most if not all people with drug and alcohol issues. Another emphasised a point already made above, namely, that self-neglect was not routinely recorded but managed through routine care management processes, which made it difficult to identify specific numbers or cases. A third noted that self-neglect is not within the *No Secrets* definition of abuse of a vulnerable adult, but that safeguarding procedures could in some self-neglect cases be useful in assessing risk and coordinating information sharing and planning where normal care management processes have proved ineffective. What emerges here again is, therefore, both a continuum of response, from care management to adult safeguarding, and recognition that self-neglect might be appropriately located within an adult safeguarding umbrella.

3.3.3 What estimation of the volume of self-neglect work?

Respondents were asked what volume of self-neglect work was being managed by their authority and/or its close partner agencies, drawing on their data or (in the absence of data) their best estimate. They chose to answer in three ways, as follows.

An estimate at a current point in time

Fourteen respondents gave a figure at a point in time. Figures ranged from 1 to 3,200 cases (see Table 5). Responses illustrate themes that appear elsewhere, both in the survey itself and the wider report, namely, the challenge of data collection on self-neglect, the difficulty of definition and whether hoarding is seen separately, and the value of panels.

- “We have nine cases but these are the extreme end where normal routes of engagement via social work teams are not working and there are significant risk issues.”
- “We do not keep specific information on how many cases are held by teams under care management and involve self-neglect. In the last 18 months since we started to hold high risk self-neglect meetings there have been 22 cases which are looked at in a multi-disciplinary forum chaired by a member of the LSAB.”
- “My team currently is working with 64 hoarders who score 6+ or more on the Clutter Rating Index.”
- “The number of people we are currently working with fluctuates from time to time, but currently we can advise around 198 across adult social care. The figure includes people who make a conscious and voluntary choice to self-neglect as a matter of lifestyle, personal preference or religious belief, and who understand the consequences of their decision.”

- “The number of referrals recorded in 2012/13, which had self-neglect recorded as type of abuse, was 254. Of these 156 went on to an investigation, but would have been reported as ‘neglect’ for the purposes of the AVA return for 2012/13.”
- “Around 94 cases are flagged up on the system. However, at present the system is not set up in a way which allows the flag of ‘self-neglect’ to be reviewed, that is, whether this is still an accurate representation of the person’s situation.”
- “Considerable work has been undertaken by one of our senior environmental protection officers to raise awareness and to develop partnership working. This officer has seen his workload increase substantially over the last 18–24 months from one or two active cases to in excess of 20 active cases, some of which involve young families. This is an estimate – better data should be available later this year.”

A percentage value of total cases

Eleven respondents replied giving a percentage value of total cases. Values ranged from 2 to 50 per cent (see Table 5). One respondent gave an estimate of 40–50 per cent and four gave an estimate of between 18.5–25 per cent. A further four estimated 10 per cent of cases, one estimated 5 per cent and another 2–3 per cent. The respondent giving the highest percentage value gave the following rationale:

- “Approximately 40–50 per cent of the cases we see have some level of self-neglect/hoarding or living in poor conditions.”

Volume per annum

Five respondents gave an estimate of volume in a period of time. Their estimations ranged from 2 to 250 cases (see Table 5). Once again, respondents here found it hard to quantify the volume of cases “without manually manipulating the data.” One estimated that approximately half of all people using mental health services on the Care Programme Approach (CPA) had varying degrees of self-neglect.

Other responses regarding volume

Two respondents gave a response that fell into two of the three categories above:

- “The census shows there are currently 17,325 carers and therefore if 18.5 per cent neglected themselves, this would suggest about 3,200 carers are neglecting themselves.”
- “Our estimate would be that self-neglect is an aspect in 25 per cent of the cases that we work with. In 2012/13 we offered assistance in 4,800 cases, which would mean that self-neglect would be an aspect in 1,200 cases.”

Four responded ‘not applicable’. However, a majority of 21 respondents said that they were unable to make an estimate (see Table 5). Justifications of why they were unable to answer included lack of confidence in estimating volume, while suggesting it might be significant, or the exclusion by the LSAB of self-neglect from its terms of reference. Thus, both exact numbers and guess work were problematic because self-neglect was excluded from safeguarding guidelines, or not recorded as a

separate category either within care management or adult safeguarding. In other words, information gathering was insufficient to provide reliable estimates, but the problem of how wide or narrow to draw the boundaries also added to the complexity, for example, with respect to drug and alcohol services and work with people with learning disabilities or older people with cognitive issues. Nonetheless, some respondents were of the view that numbers would be substantial without the intervention of social services because this work involved the meeting of eligible social care needs, due to physical ability or mental capacity issues.

Table 5: Response type, frequencies and ranges of responses regarding estimating the volume of cases of self-neglect

Question 5 By either drawing on your data, or (if you do not collect data) giving your best estimate), what is the volume of self-neglect cases being managed by your local authority and/or agencies with which the authority works closely?	Response type	Number of responses	Range of responses
	1. An estimate at a current point in time	14	1–3,200 cases at any point in time
	2. A percentage value of total cases	11	2–50% of cases
	3. Volume in a period of time	5	2–250 cases pa
	Said they were unable to estimate	21	n/a
	Said question was n/a	4	n/a
Note: Two respondents gave answers falling into more than one category, so the total number of responses here is 55.			

3.3.4 What degree of confidence in this estimation?

Respondents were asked how confident they were in their answer about the volume of self-neglect work. Only five authorities (9.4 per cent) were 'very confident' in their response. Responses were spread fairly evenly between the other three response categories: 16 (30.2 per cent) were 'fairly confident'; 14 (26.4 per cent) were 'not very confident' and 18 (34.0 per cent) were 'not at all confident' in their response to this question (see Table 6).

Table 6: Frequencies and percentages of responses to confidence of estimating volume of cases of self-neglect

Question 6 How confident are you in your answer about the volume of self-neglect cases?	Response	Number of responses	Response %
	Very confident	5	9.4
	Fairly confident	16	30.2
	Not very confident	14	26.4
	Not at all confident	18	34.0
	Total	53	100

3.4 Classification: Is self-neglect explicitly defined?

Respondents were asked whether they explicitly defined self-neglect, or provided examples in their guidance. Slightly more than half of the authorities who responded (52.8 per cent) said that self-neglect is either explicitly defined, or that examples were provided in their guidance or protocols (see Table 7).

Table 7: Frequencies and percentages of responses to Question 7

Question 7 Is self-neglect explicitly defined, or are examples provided, in any of your guidance and/or protocols?	Response	Number of responses	Response %
	No	25	47.2
	Yes	28	52.8
Total		53	100

Of the 28 respondents who answered yes, 17 provided their definition. These are categorised by the type of policy/guidance in which they are included, if this information was provided. Two others did not provide a definition but noted use of case examples/signs regarding self-neglect. Ten gave information on policy that addressed it, but no definition or further information. Three respondents who answered no also provided further information.

Definitions provided – by policy/guidance type (n=17)

In specific self-neglect policy/guidance

These definitions, many of which were agreed by individual LSABs, showed considerable overlap as they drew on research that had scoped the evidence on self-neglect (Braye *et al*, 2011a). They therefore referred to a person's inability or unwillingness to maintain care of self and/or the environment. Some referred to different manifestations of self-neglect, such as hoarding or living in squalor, and some mentioned refusal to engage with, or disengagement from support, services and/or treatment.

Safeguarding policy

Once again, the definitions drew on the earlier scoping study of self-neglect (Braye *et al*, 2011a), with reference to neglect of self and/or one's environment through inability or unwillingness to engage. One definition referred specifically to what might

lie behind self-neglect, such as traumatic life events or a struggle to preserve continuity of identity, again drawing on the earlier scoping study. There were two mentions of a Vulnerable Adult Risk Management (VARM) system for handling such cases.

Mental health clinical risk assessment

One respondent commented that in their local authority area only the mental health NHS foundation trust had a definition of self-neglect.

Community care assessment tool

One respondent referred to the local authority's community care assessment tool as enabling identification of self-neglect through the use of set questions. This approach was described as attempting:

“... to establish whether the adult they are assessing has an inability due to physical or mental impairment or diminished capacity to perform essential self-care tasks including shopping, attending to their medical care, taking care of their physical health, general safety and/or managing their own financial affairs. The assessment process also identifies whether the person is making a conscious and voluntary choice to self-neglect as a matter of lifestyle, personal preference or religious belief and understands the consequences of their decision.”

Nature of guidance/protocol not specified

Once again, guidance drew on the earlier scoping study (Braye *et al*, 2011a). Thus, “self-neglect may be conceptualised as a person’s inability to perform essential self-care tasks, both in relation to themselves and their immediate living environment. It may also include behaviour or lifestyles which conflict with social norms.” One respondent noted that their policy advised escalation to senior managers where there was a high risk of serious injury or death with respect to the individual or others. Another referred to the availability of a risk matrix and to the importance of a multi-agency framework for the sharing of information and capacity assessments.

Use of case examples/signs regarding self-neglect (n=2)

Here respondents referred to case examples being used rather than formal definitions of self-neglect, coupled with signs and symptoms such as squalid conditions, untreated injuries or poor personal hygiene. Case discussion with senior managers was advised. One respondent saw this type of work as “the core of adult social work.”

No actual definition provided, but noted where issue is addressed (n=10)

Self-neglect policy (n=2; one in operation, one in development)

The issue of whether self-neglect falls within or outside safeguarding emerged again here. One local authority reported that the Adult Safeguarding Unit screened all self-neglect referrals. One respondent referred to the development of guidance on how to work with people who will not engage, which addressed how such an approach would fit with the Human Rights Act 1998 and self-determination principles.

Safeguarding policies (n=8)

Here the focus was less on definition than on the provision of guidance, with particular reference to capacity/non-capacity, training, and risk management protocols and tools. Sometimes specific reference was made to self-neglect falling outside safeguarding criteria.

No further information provided (n=3)

One respondent noted that work was underway to define self-neglect and to create a policy for people who were vulnerable to issues of self-neglect. Two others noted that self-neglect was mentioned in safeguarding guidance. Here recurring themes emerged again. One approach specifically referred to safeguarding procedures being used where other health and social care processes had not been able to mitigate risk of serious self-neglect that could result in significant harm. Another expressly noted that self-neglect involved adults with capacity to make relevant decisions but refusing essential services without which their needs cannot be met.

3.5 Guidance to staff

3.5.1 Is guidance provided to staff on working with self-neglect?

The majority of respondents (66.0 per cent) said that guidance is provided to staff working with self-neglect (see Table 8).

Table 8: Frequencies and percentages of responses to Question 8

Question 8 Is guidance provided to staff on working with self-neglect?	Response	Number of responses	Response %
	No	18	34.0
	Yes	35	66.0
Total		53	100

All of the 35 respondents who said they provided guidance provided qualitative information on this. It was addressed through specific self-neglect guidance (9 in place, 5 in development); in general safeguarding policies ($n=8$); VARM ($n=3$); mental health and mental capacity ($n=3$); in training ($n=3$); other ($n=1$) or was not specified ($n=3$).

Specific self-neglect guidance (9 in place, 5 in development)

Respondents referred to, and sometimes gave links for, protocols, practice and policy guides. These variously covered high-risk cases, managing self-neglect and mental capacity, hoarding and managing complex cases, particularly where people were refusing services. Some were addressed to the multi-agency network and some to specific social work or integrated teams. Occasionally, reference was also made to regional policies or procedures or to safeguarding training that contained a module on self-neglect, which all qualified staff had to attend. Some documents were in draft form and awaiting final approval. Securing multi-agency agreement was sometimes proving problematic.

Safeguarding guidance (n=8)

Sometimes this was referred to as offering general information, or even as being limited in respect of self-neglect; at other times it provided detailed multi-agency

policy and procedures, with advice to ensure a full assessment of needs, drawing on SCRs and previous research.

VARM (n=3)

This framework was distributed to staff in adult social care and sometimes beyond. One respondent commented that the approach was specifically intended for high-risk non-engagers. Another gave extensive detail, namely, that the framework had been developed by the LSAB to support effective joined-up working across agencies in situations of risk that require multi-agency support. The model offers clear principles and values, a framework for assessment and management of risk and guidance on core elements of practice that will underpin risk work in all agencies. It encourages joint working to bring information and capability from all agencies, particularly in situations of high risk or intransigent situations. It is intended that it be accepted by all agencies as a baseline to support effective multi-agency working.

A section of the framework is specific to self-neglect and situations where support is declined. There is clear guidance for practitioners on what to do in these situations, and a flow chart to help them with this. The guidance requires that, if an adult at risk refuses or declines an assessment, services or support, a risk assessment must be carried out to determine the level of seriousness of each identified risk. Intervention must be person-centred, involving the individual as far as possible in understanding the risk assessment and the alternatives for managing the risk. Information should be shared with other relevant professionals who may have a contribution to make in managing or monitoring the risks. Consideration must be given to the mental capacity of the individual and whether they require support in their decision making or, following an assessment that the individual lacks capacity, whether a best interests decision might be appropriate.

Mental health and mental capacity (n=3)

Two examples covered guidance from Mental Capacity Act 2005 training on how to assess needs and capacity; the third referred to the CPA and Clinical Risk Assessment and Management guidance for mental health practitioners.

Addressed in training (n=3)

In the absence of specific guidance, and sometimes alongside it, training would address self-neglect when focused on risk assessment, mental health and/or older people. Training materials were sometimes reported as available on health and adult social care intranets. In one instance, materials addressed definitions of self-neglect within a multi-agency policy and procedure for adults at risk.

Other (n=1)

This respondent referred to fire crews needing to refer self-neglect cases to social care.

Not specified (n=3)

Two references here were to websites. A third noted the absence of formal written guidance but commented that staff were encouraged to raise issues and seek advice from a safeguarding duty desk or locality safeguarding consultant practitioner, highlighting references elsewhere in this report to the importance of being able to access specialists. This respondent noted that self-neglect was not seen as safeguarding but was, nonetheless, an important issue, not to be ignored.

Of those who answered no

Five of the 18 who did not provide guidance for staff provided additional qualitative information on this question. Two noted they were developing specific policies and procedures for practitioners in managing cases of self-neglect. Of the other three, one referred to Fair Access to Care Services (FACS) eligibility criteria, one to guidance and support on an individual basis through an approach which combined risk management, supervision and person-centred planning, and the third to guidance available under the Mental Health Act 1983 and Mental Capacity Act 2005.

3.5.2 Is other guidance relevant to self-neglect work?

Respondents were asked whether they had definitions or examples of self-neglect in other guidance. The majority of respondents (64.2 per cent) were not aware of other relevant definitions or examples related to self-neglect in their guidance or protocols (see Table 9).

Table 9: Frequencies and percentages of responses to Question 9

Question 9 Are there other relevant definitions or examples, not specifically defined as self-neglect but related to it, in any of your guidance and/or protocols? This might include hoarding, living in squalor, or other phenomena that you feel are relevant?	Response	Number of responses	Response %
	No	34	64.2
	Yes	19	35.8
Total		53	100

All 19 respondents who answered yes (35.8 per cent) provided qualitative information. Hoarding was identified by just over half ($n=10$) and social isolation/loneliness by two. Other information provided is noted below.

Hoarding (n=10)

Here, references were made to policies, sometimes still under development, that covered people who hoard excessively, and people living in a squalid or unhygienic environment, thereby triggering health and safety concerns. Policies had been, or were being, developed by representatives from across agencies, including healthcare providers and commissioners, public health, adult social services, housing and environmental services. Hoarding protocols were sometimes accompanied by a hoarding assessment tool, which used the Clutter Rating Index, and by the creation of specific panels to which cases could be taken for discussion. Fire risk and service refusal were referred to in this context as adding to case complexity and emphasising the importance of a multi-agency approach. In this context, one respondent referred to the absence of specific information in policy, but to custom and practice in the domain of self-neglect associated with squalor and hoarding, which involved joint working with housing and environmental health.

Social isolation/loneliness (n=2)

One of the two references here referred to an independent living and extra care housing strategy that picked up on concerns regarding social isolation and loneliness, and a potential link to adult safeguarding.

“Social isolation and loneliness are also emergent policy concerns which local authorities and their partners will need to measure and address. There are clear issues for people’s physical and mental health and their ability to live independently with a reasonable quality of life. In seeking to extend people’s independence care must be taken to ensure that people do not become isolated with an increased risk of loneliness and harm. In implementing this strategy, commissioners and providers will need to consider this both in respect of support to people in their homes and in the provision of additional independent living options.”

Generic safeguarding

Reference here was to safeguarding guidance, highlighting again that self-neglect was sometimes given a strategic and operational home under an LSAB. One safeguarding policy and procedures document was quoted here:

“Self-neglect on the part of an adult at risk will not usually lead to the initiation of adult protection procedures unless the situation involves a significant act of commission or omission by someone else with established responsibility for the adult’s care. Other assessment and review procedures, including risk assessment procedures, may prove a more appropriate intervention in situations of self-neglect.”

Other

References here were to VARM systems, harm and significant harm as defined in local self-neglect policy, and to a policy on risk enablement. This was described as a policy around balancing the choices people make and the risks that may occur. It included a section on ‘Refusal of Care or Treatment and Self-neglect’. It does not offer a definition, but gives examples of different characteristics and behaviours of self-neglect, and addresses the need to make use of risk assessment tools to manage the risks where self-neglect (avoidable deterioration in health and/or social care needs) is occurring. It reminds readers that poor environmental and personal hygiene may not necessarily always be as a result of self-neglect, but could arise from cognitive impairment, physical ill health, financial constraints or personal choice or lifestyle. In addition, it observes that many people, particularly older people, who self-neglect may lack the ability and/or confidence to come forward to ask for help; they may also lack others who can advocate or speak for them. They may then refuse help or support when offered or receive services that do not actually adequately meet their needs. The same respondent referred to a housing policy on managing hoarding behaviour that set out how this behaviour manifests itself, and the need to link with social services if the resident appears to be somebody who may be at risk. Another respondent made reference to self-neglect and legal materials available through the Social Care Institute for Excellence (SCIE) website. One respondent who answered ‘no’ also stated that the local authority had provided workshops to help raise awareness among professionals.

3.6 What is most challenging about self-neglect work?

Respondents were asked what, in their experience, were the most challenging aspects of self-neglect work for the authority and/or their partner agencies. Here the

data was exclusively qualitative and comprised responses on the survey form and from interviews with respondents where they offered follow-up contact. Fifty respondents identified challenges. These most frequently centred round the issue of capacity and related challenges. Categories inevitably overlap but have been broken down into different elements for clarity.

Challenges around capacity and refusal to accept help

These were identified by 40 respondents. The themes involve cases where the person at risk has mental capacity and is making unwise decisions, or cases where capacity fluctuates. This then leads into ethical territory where the rights of the individual have to be balanced with a duty of care. Other people's or agencies' expectations, namely, that 'something should be done', might have to be managed here too. Respondents thought that there was a need for better understanding of mental capacity and of case law, and a greater use of the Mental Capacity Act 2005 to protect personal welfare. Also mentioned in this context was the importance of a thorough risk assessment and multi-agency discussions before any organisation withdraws. Where possible, the views of the person involved and relatives should be sought, a clear reference to person-centred care.

One case example was offered to illustrate the challenges here. The respondent refers to the balance needing to be struck between human rights and self-determination, on the one hand, and the role of the state, on the other. They ask:

"When is the point of intervention for social workers, when the habits of an alcoholic, single man have led to inviting strangers into his property who in turn 'exploit' that man's finances and steal possessions, but the person does not recognise it as a problem? This type of dilemma creates tension in the role of adult social care [especially in the creation of 'solution expectations'] and the actions for social workers/care management in decisions made face-to-face with the person as to what should, if anything, be done."

Reluctance to engage with services

Here once again the focus was on working with those who have capacity but who are reluctant to engage with services and support, but also with the challenge of the tipping point between capacity and incapacity, which could be difficult to judge. These challenges could be further complicated by agencies terminating their involvement with the individual because of their refusal to engage. Cases were made additionally difficult because of the ethical dilemma of balancing self-determination with a duty of care, and how to effect change when behaviours have become entrenched and intractable, resistant to intervention. They might also make high demands on emergency services, such as the police and ambulance service, which would then trigger agency expectations that also required management. Sometimes guidance suggested convening multi-disciplinary meetings, consulting with legal services, and recording what interventions had taken place.

Level of risk

Two respondents mentioned cases where people were deemed to have had capacity and refused services, which ultimately led to their deaths and strong challenges from the Coroner's Court. Two other respondents referred to people dying as a result of their choices despite effective joint working, with one authority having commissioned

two SCRs and the respondent noting that, “self-neglect cases can be some of the most risky for the authority.”

Expectations of others

Expectations might come from family members or the public reluctant to accept the decisions of someone with capacity and wishing to override their choices. Partner agencies may also have expectations that could prove similarly difficult to manage.

Limited options available to enforce support

This was a challenge identified by 11 respondents. Here the focus again is on capacitated people's reluctance to engage and the perception conveyed by respondents that options are limited. This may reside in limited authority to take action to reduce risk, the lack of and/or the diffused nature of a legal framework to support the process other than mental capacity legislation and limited power of entry other than under the Mental Health Act 1983. More training and understanding of case law and the Court of Protection was thought to be useful, highlighting the point about legal literacy made elsewhere in this report. Legal mandates that were available were also problematic:

“The legal framework for intervening is diffused and tends to be based around an environmental health approach to the problem. Also, where notice of seeking possession is leading to eviction, the Courts are very reluctant to evict where alternative accommodation is not already in place, which might include residential care [but the person may well not be willing to move or be sufficiently frail].”

“One of the greatest issues is that of enforcement; where squalor and neglect impact most is within a social housing setting where eviction is often the only statutory instrument for enforcement. If in private housing little can or will be done unless environmental health can and will intervene.”

A further challenge referred to here related to people, such as those misusing substances, who had no will or incentive to engage with workers, irrespective of which agencies they were from.

Challenges related to service responses

These were identified by 15 respondents. Several themes appear or re-emerge. One set of challenges relates to having the time to build trust and relationships with adults who self-neglect; care management systems focus on episodes, and self-neglect cases are not generally amenable to quick solutions. Another set of challenges relate to inter-agency working – sometimes this was felt to be absent, with services pursuing their own remit, failing to collaborate or using their eligibility criteria as a means to ‘pass the buck’. It could prove challenging to secure attendance by agencies at meetings and case conferences. Equally, specialist services, such as psychological therapy and mental health provision, might have long waiting lists or prove difficult to engage with self-neglect cases. A third set of challenges involved knowing how to intervene when people might not meet eligibility criteria, or when they have capacity and are refusing help. Other agencies might have expectations that would have to be managed. Adult social care staff might have to record that everything that could reasonably and proportionately have been done had been

tried, without success. Here, practitioners might have to work hard to help people to understand the consequences of their actions. Finally, it could be hard to locate resources to fund repairs, replacement furniture or blitz cleans.

Where self-neglect sits in the system (safeguarding or not)

Five respondents identified this as a challenge. Here the theme of location recurs, with some authorities locating self-neglect in safeguarding and some not. The theme of care management also resurfaces, with concerns that cases often do not meet the safeguarding or eligibility criteria thresholds, and the people involved are capacitated regarding decisions around self-care. This led some respondents into discussion of ethical issues that add complexity to this work.

“The desire to make this an adult safeguarding issue has obscured a discussion about identifying the right people to address the issue and the need to consider the individual’s mental capacity in relation to the decisions made or not made to address their situation.”

“The most challenging issue is that some partner agencies do not recognise self-neglect as a safeguarding issue.... They ignore capacity issues or fail to properly risk assess the situation and rush to raise a safeguarding referral, often without the knowledge or consent of the service user.”

Inadequate policies/procedures

This challenge was identified by four respondents, focusing on views that the eligibility criteria and the care management process did not facilitate effective work with those who refuse services where what is needed is professional support rather than a commissioned package of care. One respondent commented that self-neglect was not a defined category within safeguarding, which meant that there were no formal processes to manage such cases. They might be managed within safeguarding or routine casework, again highlighting the question of where such work is owned or where it sits within the system.

Professional confidence (n=1)

One person identified that practitioners lack confidence in their understanding of law and of their authority in self-neglect cases.

Other

One respondent observed that it proved difficult to prevent a re-occurrence of the same issues following a return from hospital and/or a blitz clean, which reinforces the observation that practitioners and managers make elsewhere in the report, that effective interventions need to understand what drives the self-neglect behaviour. One respondent observed that what was offered could be a postcode lottery.

3.7 Staff training

Respondents were asked whether training was available to assist staff in working with self-neglect. The majority (77.4 per cent) of respondents said there was either no training available, or that there was no *specific* training available, leaving only 22.6 per cent (around a fifth) who identified available self-neglect training (see Table 10).

Table 10: Frequencies and percentages of responses for question 11

Question 11 Is training available to assist staff in working with self-neglect issues?	Response	Number of responses	Response %
	No	16	30.2
	Yes	12	22.6
	Not specifically	25	47.2
Total		53	100

Qualitative responses have been categorised as specific self-neglect training currently delivered ($n=10$ in qualitative data; two other respondents answered 'yes' to training but one had not yet set this up, and the other provided no further detail); specific self-neglect training in development ($n=2$); self-neglect covered in general safeguarding training and Mental Capacity Act/mental health training ($n=9$); and self-neglect covered in general safeguarding training ($n=12$).

Specific self-neglect training ($n=10$)

Reference here was to commissioned external researchers, or to local managers and specialist environmental health, safeguarding or mental health professionals, who had provided day or half-day learning events focusing on self-neglect cases, sometimes with specific reference to hoarding or mental capacity. These events had sometimes been triggered by SCRs or a refusal of services-related death, and sometimes by the development and launch of self-neglect procedures. One respondent referred to two successful conferences that had been organised by the Safeguarding Adults Team. Two respondents referred to differentiated levels of training, from basic awareness to engaging with complex work, depending on people's roles.

Specific self-neglect training in development ($n=2$)

Again the intention to commission training might be triggered by a current SCR or the launch of a newly developed policy, for example, relating to risk management and recording, which required rolling out to all operational staff in healthcare and social care.

Covered in general adult safeguarding training ($n=12$)

Here self-neglect might be mentioned in safeguarding awareness, something to be risk-assessed and case-managed, but not necessarily seen as safeguarding *per se*. Reference was also made to Mental Capacity and deprivation of liberty safeguards (DoLS) training, where workers could raise concerns about practice dilemmas, or to briefings about the establishment of panels and forums where complex cases involving vulnerable adults could be discussed. The intention here was for the local authority and its partner agencies to look at problem cases where complex issues had become entrenched such that individual practitioners were finding them irresolvable, but where a multi-agency approach, with senior manager involvement, might find a way forward.

Covered in general safeguarding and mental capacity/health training ($n=9$)

Reference here was to training in safeguarding and mental capacity that might include reference to self-neglect.

Other training areas mentioned

One authority identified disabilities, welfare benefits, domestic violence, dementia, health and safety and first aid.

3.8 Processes and pathways for working with self-neglect

Respondents were asked what processes and pathways were regularly used in self-neglect work in their locality. Forty-six (86.8 per cent) authorities said they referred self-neglect cases to adult social care teams, 28 (52.8 per cent) consider a safeguarding alert, 11 (20.8 per cent) refer to MARAC and 30 (56.6 per cent) gave details of other processes and pathways (see Table 11).

Table 11: Frequencies and percentages of responses for question 12

Question 12 What processes/pathways are regularly used as ways of working with self-neglect in your locality?	Safeguarding alert	28	52.8%
	MARAC	11	20.8%
	Referral to adult social care teams	46	86.8%
	Other (<i>please specify</i>)	30	56.6%
Note: respondents are permitted to make more than one response to this question, so the total will be more than 53 (100%)			

Looking at all three processes/pathways listed (safeguarding alert, MARAC or referral to adult social care teams), 20 (37.8 per cent) used one of the three; another 19 (35.8 per cent) used two of the three; while 9 (17.0 per cent) used all three. Only 5 (9.4 per cent) did not use any of the three (see Table 12).

Table 12: Showing number (%) of local authorities who use none, one or more of the following three processes/pathways: safeguarding alert; MARAC; referral to adult social care teams

Question 12 What processes/pathways are regularly used as ways of working with self-neglect in your locality: safeguarding alert; MARAC; referral to adult social care teams	Number of respondents (n=53)	% of total responses
None of the three	5	9.4
One of the three	20	37.8
Two of the three	19	35.8
All three	9	17.0

Comments on use/non-use of safeguarding (also includes data on adult social care) came from nine different sources

The continuum between safeguarding and social care approaches is once again evident. All respondents noted that self-neglect was not seen operationally as a safeguarding issue *per se*, with safeguarding procedures used for high-risk cases where multi-agency or integrated network approaches, including complex case management work, had failed to make progress in managing risks and addressing care needs.

Comments on referral to, and work coordinated by, adult social care teams

Here reference was made to referrals to adult social care teams, sometimes involving joint work with housing and environmental health, underpinned by protocols for working with adults at risk who do not wish to engage with services. This was seen as providing a pathway for risk assessment and management, including, where necessary, capacity assessment and best interests decisions. It could also be underpinned by panels with the remit to consider cases involving high-risk and/or chaotic lifestyles, with the aim of agencies sharing information and developing risk management and creative engagement strategies, often with respect to individuals who may not otherwise meet resource eligibility criteria. The focus was also on avoiding partners working in isolation and on learning lessons from practice on how to more effectively meet the needs of individuals who live lifestyles that engender high levels of risk. One respondent noted in passing that deep cleans had been used on occasion, but often this addressed only the short-term issue as opposed to getting to the bottom of the underlying psychology.

VARM

Four respondents identified this multi-agency approach. In this context one also referred to the Dementia Care pathway in that this was part of the local response to the needs for a national dementia strategy, and many older people, living in their own homes, start to struggle with self-care of hygiene, meals, medication/health and their environment due to onset of dementia. Thus the local authority, in its Adult Social Care pathway, had created dementia care advisers who make early contact with individuals who have been recently diagnosed with dementia to discuss and work on supports that may be required, but who may not have social care needs presenting at that point. This work is preventative of the otherwise crisis intervention work that can take place when problems, such as self-neglect, eventually become overwhelming.

MARAC

Two respondents expressed surprise at the idea of using MARAC in the context of self-neglect. A third commented that they had used it rarely when working jointly with police, environmental health, housing and community services.

Mental health/capacity assessments

Five respondents commented on referral to GP or mental health colleagues for assessment of capacity and use of best interest decisions, and employment of the CPA for more complex and long-term cases. Once again, panels and professional meetings were mentioned as a way of assessing and managing risk.

Other pathways

Individual mentions here from six respondents related to referrals to or from the Citizens' Advice Bureau (CAB), housing, support groups, and the fire service, as well as to community safety or voluntary sector initiatives. One respondent referred to a service offered by Age UK, designed to enable people to remain safely in their own homes and independent for as long as they wish, and to help improve their quality of life. On receipt of a referral in relation to someone who is self-neglecting, hoarding or living in unsafe or substandard accommodation, the service will make contact, make referrals to environmental health and the fire service, and seek to support people. This may involve multi-agency meetings and sharing of costs to clean up and

replace furniture. Once again, a panel or forum is used to which people who are self-neglecting, hoarding, living in squalor or sub-standard accommodation can be referred. Set up by the Community Safety Partnership and LSAB to effectively case manage and provide a multi-agency response to vulnerable individuals, it coordinates services in response to the identified needs of individuals in order to prevent, protect and address behaviour affecting them and/or to address their needs by appointing a lead agency to manage and coordinate each case, promoting positive action to support people and, if necessary, to deal with any people causing harm, and actively encouraging community-based solutions to develop social cohesion. Available interventions include: preventative measures, such as use of support equipment; enforcement when necessary and proportionate; and referrals on to appropriate services, including adult and children's safeguarding.

3.9 Data on self-neglect outcomes

Only 8 (15.1 per cent) authorities held data on outcomes of self-neglect cases (see Table 13).

Table 13: Frequencies and percentages of responses for question 13

Question 13 Is data held on outcomes of self-neglect cases (collectively, not individually)?	Response	Number of responses	Response %
	No	45	84.9
	Yes	8	15.1
Total		53	100

Of those respondents who responded affirmatively, seven provided further information. No distinctive pattern emerges from these responses. One respondent thought that generally the outcomes had been positive, with some intervention having taken place and risks managed or reduced. All cases had demonstrated comprehensive risk and capacity assessments and consideration of duty of care and legal routes. Another suggested that data on outcomes were held in care management teams, which then constitute part of the discussion in performance management meetings where appropriate. There was also opportunity for wider discussion with other managers where a lesson from a particular case needs to be shared. A third suggested that outcomes were only readily captured where serious self-neglect had triggered a safeguarding investigation. Similarly, others commented that outcomes may only be very general – the number of cases, the reason for service use, general level of satisfaction, changes in support – or not captured routinely, as referrals do not always result in feedback.

Of those respondents who replied in the negative, six provided further information. Some were unaware of any outcome data while others noted that learning would involve a manual trawl through data as outcomes of self-neglect work lay outside the Safeguarding Annual Return. Nonetheless, the data that could be extracted would be useful when updating policies and procedures.

3.10 Serious case reviews in self-neglect

Respondents were asked whether self-neglect had been a feature of any serious case review undertaken in their area. Fifteen (28.3 per cent) reported that self-neglect had been a feature of any SCRs in their area (see Table 14).

Table 14: Frequencies and percentages of responses for question 14

Question 14 Has self-neglect been a feature of any serious case reviews undertaken in your area?	Response	Number of responses	Response %
	No	38	71.7
	Yes	15	28.3
Total		53	100

All 15 respondents who were aware of an SCR in their locality provided further qualitative responses. Some identified the key messages from the SCR, for instance, relating to capacity, communication and information sharing, gaps in multi-agency working, the importance of chronology and historical factors on a person's current presentation, and the need for joint working to manage risk related to self-neglect and to develop assertive care plans seeking engagement with individuals who are reluctant to accept help from agencies. SCRs had also stressed the importance of escalation, to ensure that senior managers are aware of high-risk cases, and of genuine multi-disciplinary engagement as opposed to reliance solely on adult social care. Others noted that an SCR had led to policy and practice guidance development, for example, on risk assessment and management, or information sharing, and the provision of training, for instance, covering service refusal and disengagement, identification of self-neglect and understanding of mental capacity and risk assessments. One respondent noted, however, that a bigger challenge than the development of protocols lay in securing resources and ensuring that staff across agencies implemented policies.

One respondent gave a detailed response of how an SCR had triggered multi-agency discussions and good practice guidance relating to use of advocates, involvement where possible of family members and community networks, and a comprehensive assessment that included observation of the home and of a person's functional and cognitive abilities. The respondent stressed the importance of using a range of services and specialists, depending on the case, recording all efforts and actions, especially in the context of service refusal, and providing individuals with information about possible options and services. Panels had been established with the purpose of managing risk positively and proportionately, especially in cases where a person did not have capacity or where it was fluctuating. Once again, this emphasises the benefits to be gained from panel discussions in terms of sharing and managing risks, overcoming barriers between agencies, identifying areas of good practice and disseminating effective ways of joint working.

Five who answered 'no' nonetheless provided further information. They referred to various types of case review that had been undertaken to learn organisational lessons, such as the importance of robust capacity assessments, multi-agency training, and the need to understand other agencies' roles, including environmental health and the fire service.

3.11 Learning from practice

3.11.1 Do you know of referral systems and pathways in your area that you feel have worked particularly well either in individual self-neglect cases or with self-neglect more generally?

The majority (66.0 per cent) of respondents said they were aware of referral systems and pathways in their area that had worked particularly well, either in individual self-neglect cases or with self-neglect more generally (see Table 15).

Table 15: Frequencies and percentages of responses for question 15

Question 15 Do you know of referral systems and pathways in your area that you feel have worked particularly well either in individual self-neglect cases or with self-neglect more generally?	Response	Number of responses	Response %
	No	18	34.0
	Yes	35	66.0
Total		53	100

Fourteen respondents mentioned multi-agency working. Other category responses were as follows.

VARM

Six respondents referred to this approach, which had been implemented or was being piloted. There was some evidence that it was having an impact, picking up cases where the Mental Capacity Act 2005 or Mental Health Act 1983 were less applicable, and enabling a number of individuals to engage, for example, by accepting low-level practical support, through the use of assertive outreach. The model appeared helpful too when other processes for joint working were breaking down. One respondent also observed that panels to which complex cases could be taken were also helpful in highlighting gaps in services, poor information sharing and fragmented risk management, and in promoting shared ownership of solution and ongoing monitoring of complex cases.

Protocols

Protocols on safeguarding vulnerable adults had been used to bring partners together, although not all respondents were confident that practitioners would be familiar with them. Again, there were differences of emphasis between those who saw community care assessment, CPA, review and risk assessment procedures as generally the best route, because people who use services might perceive them as supportive and non-threatening, and those who favoured the safeguarding pathway in order to engage agencies and to work with the individual to acknowledge their need for support and input. Either way, guidance was seen as giving staff a process or pathway to follow, and therefore a stronger sense of control over what to do and who to involve. Legal options were pursued when offering the least restrictive and proportional intervention.

Policy

Two respondents referred to policies on high-risk and non-engagers, or multi-agency working, with evidence that they had enabled agencies to work together to monitor

and manage high-risk situations, complete more thorough assessments of risk, and achieve better outcomes for people who use services.

Safeguarding process

Three respondents referred to using safeguarding referrals or processes to deal with these cases and provide a multi-agency forum.

Hoarding/fire brigade

The fire service may be the first point of contact. Hoarding posed a potential fire risk and required a speedy multi-agency response coupled with innovative and creative ways of working with a service user. One respondent noted that there had been cases where there had been an issue of hoarding and Adult Services had worked with the fire brigade to put in place practical interventions to support an individual and to try and reduce the risk of a fire happening in the property and surrounding properties. Working with mental health services to provide therapeutic support to an individual who had an established behaviour of self-neglect was also essential, with practitioners being persistent in engaging the individual and using a multi-disciplinary approach to tackle the issues.

Single access point

Two examples were given. One was a pilot of a new single front door into adult social care, creating a central point of contact on all referrals, ensuring requests are quickly responded with consistency and clearly defined plan of actions. Having the Initial Contact Service (ICS) had enabled the police, fire service and ambulance service to have a central point of contact where all referrals are sent, of which a significant proportion related to people who are self-neglecting. Since the creation of ICS, collaborative working with these partners has significantly improved the handling of self-neglect cases. The other initiative referred to a multi-agency safeguarding hub to capture all safeguarding referrals through a single front door – promoting ease of referral and oversight of cases by specialist workers.

Risk panel

Two respondents once again referred to the benefits of panels to which practitioners can refer concerns about risks including self-neglect. A multi-disciplinary approach is taken to ensure a holistic view of the individual and their circumstances, with a collaborative approach to offering advice, information, specialist knowledge and practical support. Practitioners were said to find this approach helpful in agreeing risk management plans and addressing their support needs.

Multi-disciplinary pathways

Here the emphasis was on multi-agency working and took various forms. One respondent referred to multi-disciplinary pathways which practitioners could use, when care planning flagged up risk of severe self-neglect, depending on the individual situation. These allowed information to be shared and identified those agencies with which the service user might be engaging. Several others referred to multi-disciplinary teams coming together to arrange a risk management plan. Care management might take the lead and liaise with housing colleagues and environmental health as appropriate, again depending on the issues. Such joint working was said to help other agencies appreciate the limitations of statutory powers available to adult social care and to improve access to mental health

assessments before consideration of such legal options as enforcement notices. These pathways were generating increased referrals from statutory partners, but one respondent noted that more work was needed to increase referral rates from family, friends and neighbours.

Other

Comments here echoed those above in the sense of advocating multi-disciplinary meetings, the use of high-risk and harm reduction panels or forums to which complex cases could be referred and building referral pathways. One such pathway involved Age UK coordinating referrals for fire safety checks, replacement furniture and equipment, environmental health and adult social care.

Some respondents who answered 'no' also gave additional information. One respondent once again commented that an SCR had triggered a review of the multi-agency strategic approach to self-neglect. Another simply suggested that a protocol informed procedure and practice while a third found it difficult to comment on areas of good practice because data specifically on self-neglect was not recorded, but that this did not mean operational staff were not using good practice or successful techniques.

3.11.2 Do you know of mechanisms for inter-agency collaboration in your area that you feel have worked particularly well either in individual self-neglect cases or with self-neglect more generally?

The majority (67.9 per cent) of respondents knew of mechanisms for inter-agency collaboration in their area that worked well (see Table 16).

Table 16: Frequencies and percentages of responses for question 16

Question 16 Do you know of mechanisms for inter-agency collaboration in your area that you feel have worked particularly well either in individual self-neglect cases or with self-neglect more generally?	Response	Number of responses	Response %
	No	17	32.1
	Yes	36	67.9
Total		53	100

Examples of successful inter-agency collaboration categories included a multi-agency panel to explore provision of appropriate support, a multi-agency protocol to define agency responsibilities, to coordinate risk assessments and to agree how best to offer support to individuals, and a multi-agency high-risk policy that sought to bring agencies together in order to share risks and to improve risk and capacity assessments. Once again, VARM was mentioned, sometimes alongside panels to which high-risk and complex cases could be referred, as having been set up to bolster inter-agency working. This had led to beneficial impacts in terms of finding creative and multi-agency solutions to previously intractable situations.

Panels indeed, once again, figured prominently. Some, focused on hoarding, had brought together housing teams, the fire service and adult social care, and had been effective in some instances in reducing hoarding or preventing eviction. Risk panels and risk registers similarly offered a multi-agency approach to discussion of concerns, a monitoring function and oversight of risk management.

The theme of the interface with safeguarding appeared again here. Some respondents commented that although self-neglect lay outside safeguarding procedures, it was useful to include it within the LSAB's strategic focus. Collaboration being led by safeguarding specialists had also proved beneficial in some cases, providing a certain "traction and administrative support" that secured participation in complex care management conferences. Other agencies, such as fire and rescue services, would make safeguarding referrals too. Once again, there was also reference to a multi-agency safeguarding hub as proving effective in engaging with partners.

Other effective mechanisms that were mentioned included care planning and, in mental health, the CPA. Work with housing teams, environmental health, safer neighbourhood teams, anti-social behaviour reduction teams and the fire service was referred to. Once again, as commented on earlier, reference was also made to the benefits of a multi-agency safeguarding hub, of clear referral pathways, and/or of panels or case conferences. These were reported as being helpful in exploring risks and generating person-centred risk management plans, and in improving the management across agencies of self-neglect work because they facilitate the sharing of organisational perspectives. For example, one respondent referred to:

"... a multi-agency housing emergency management referral where a social worker may request a meeting with other agencies to review a person's care in the community where eviction may be a route being considered. Its aim is to prevent where possible such evictions by a multi-agency approach that uses the differing elements of enforcement prior to the final solution, which is usually eviction. This is a worker-led initiative that senior management are now looking at in light of welfare reforms, and we hope to bolster and widen the agenda for earlier interventions."

Those who answered 'no' nonetheless offered further comment. Once again, an LSAB had taken a strategic lead in facilitating discussion across agencies about effective ways of working with self-neglect cases, or in establishing that safeguarding procedures could be used when other systems had not enabled progress to be achieved. And once again, attention was drawn to the value of risk assessment panels and co-location of social work and police in a hub for fast and effective information sharing.

3.11.3 Do you know of procedural guidance or training for staff in your area that you feel have worked particularly well either in individual self-neglect cases or with self-neglect more generally?

Slightly more than half of respondents (52.8 per cent) said that they did not know of procedural guidance or training for staff in their area that they felt had worked particularly well, either in individual self-neglect cases or with self-neglect more generally (see Table 17).

Table 17: Frequencies and percentages of responses for question 17

Question 17 Do you know of procedural guidance or training for staff in your area that you feel have worked particularly well either in individual self-neglect cases or with self-neglect more generally?	Response	Number of responses	Response %
	No	28	52.8
	Yes	25	47.2
Total		53	100

Comments from those respondents who answered 'yes' focused on what were now recurring themes. One theme involved the importance of training, covering, for instance, mental capacity law and assessment, self-neglect research, domestic violence, dementia and fire and safety awareness. Some local authorities were experimenting with e-learning. Another was the use of panels and forums, with a focus on mental capacity and/or complex and high-risk cases, as a means of sharing responsibility for risk management. A third theme related to the development of protocols, for example, VARM or for the management of hoarding and complex cases, which staff across social care and healthcare were said to find helpful for understanding different people's roles in self-neglect cases. Once again, an SCR had sometimes acted as the spur to the development of a multi-agency approach, for example, to risk. A fourth theme related to working closely with agencies such as the fire service on individual cases, for example, of hoarding, to identify patterns of behaviour and to seek person-centred solutions where the service user retained as much control of decision making as possible, using services and information to help them resolve problems.

Those who answered 'no' also offered commentary, to the effect that regular training was offered on mental capacity, safeguarding or risk management, which offered an opportunity for issues relating to self-neglect to be raised, for example, when someone has capacity around specific issues.

3.11.4 Do you know of approaches to direct practice in your area that you feel have worked particularly well either in individual self-neglect cases or with self-neglect more generally?

There was a fairly even split between those who did not know of approaches to direct practice in their area (50.9 per cent) that they felt had worked particularly well, and those that did (49.1 per cent) (see Table 18).

Table 18: Frequencies and percentages of responses for question 18

Question 18 Do you know of approaches to direct practice in your area that you feel have worked particularly well either in individual self-neglect cases or with self-neglect more generally?	Response	Number of responses	Response %
	No	27	50.9
	Yes	26	49.1
Total		53	100

Those who responded affirmatively offered commentary that highlighted once again themes running through the survey and the whole research report. The overarching

emphasis was two-fold. First, practice had to be relationship-based and person-centred, offering continuity of worker and time. A range of agencies and specialist interventions might then be arranged, including assertive outreach, dementia care and psychologists, depending on the causes and consequences of self-neglect. Practitioners might need to demonstrate persistence and to explore different avenues of engagement. Work might need to engage family members and community groups, with the service user fully involved in discussions of desired outcomes. Second, partner agencies had to work together to share information and plan joint action, each bringing their expertise and knowledge to contribute towards successful outcomes. This multi-agency approach would use case conferences and panel discussions, accessing specialist advice when needed from safeguarding staff. This overall approach had to be underpinned by supervision and management support, and training.

One respondent who answered ‘no’ did not think that it was possible to give a “blanket answer”.

3.12 Additional comments

Respondents were asked to comment on any aspects of self-neglect work that hadn’t featured earlier in the questionnaire. Only 8 of the 53 respondents (15.1 per cent) said that there were further aspects to their self-neglect work that had not been mentioned in this survey that they wished to comment on further (see Table 19).

Table 19: Frequencies and percentages of responses for question 19

Question19 Are there any aspects to your self-neglect work that haven’t been mentioned above on which you would like to comment?	Response	Number of responses	Response %
	No	45	84.9
	Yes	8	15.1
Total		53	100

Recurring themes resurface here. One was the difficulty of knowing how best to respond when the person who uses services has capacity but places themselves or others at significant risk. Here a legal literacy, for example, relating to use of the Court of Protection, was thought essential. Another was that self-neglect is a policy and practice arena where a stronger evidence base, leading to advice and guidance, would be welcome. A third was comment on the degree to which self-neglect policy and practice should lie within or outside of safeguarding, and the degree to which safeguarding processes may be helpful in dealing with such complex cases. A fourth was recognition that training and guidance about best practice are now being rolled out, but outcomes have yet to be captured and integrated into the evidence base locally or nationally. A fifth was the need to return to a community and relationship-based social work approach, which is seen as challenging in a context of budget constraints.

4. Managers' perspectives

Twenty managers holding strategic or operational posts were interviewed. Seventeen of these worked within the seven local authority areas originally selected. The three others were interviewed as a follow-up to the survey, which they had completed. Interviews were flexibly structured in order to be able to follow up on what was of most interest in each locality. The topic list is reproduced in Appendix 2.

Two managers in particular were especially clear about what they were hoping would emerge from the research, namely, some clarity about how to achieve good outcomes and where responsibility for working with adults who self-neglect should best reside.

"In the sense of good practice: 'this is what could be achieved,' 'this is what we'd want to be achieved.' Therefore there's a path to get to it, but actually persevere."

"I think it's about reinforcing multi-agency responsibility around things because we still, all these years on, battle with some individual practitioners' view of responsibilities around adult safeguarding. Although the policies and procedures are there, we talk multi-agency, there is still a feeling, 'That's your problem, not ours,' and we need to make sure that actually, everybody knows that it is their responsibility, their business as well."

They conveyed a sense that they were working in a policy and evidence vacuum and were hoping that the research would help to identify what might work in cases of adults who self-neglect. This section of the report draws on managers' experiences, first, by focusing the lens on strategic issues, such as policy development for multi-agency working and the management of self-neglect work, and then, by exploring operational implementation of agreed procedures.

4.1 Strategic responses

Seven key themes emerged from the managers' interviews, which highlighted the strategic issues facing those responsible for managing services: the governance of self-neglect work; building multi-agency cooperation; configuring referral pathways; turning strategy into frontline practice; collecting data; identifying triggers for strategic management action; and developing organisational objectives. These are considered in turn.

4.1.1 Governance

Some of the strategic challenges discussed by managers related to the governance of self-neglect work, presented here through three sub-themes: 'locating strategic oversight', 'commissioning serious case reviews' and 'responsibility for policy development'.

Locating strategic oversight of self-neglect

Managers recognised that self-neglect did not fall within adult safeguarding as defined by the guidance applicable at the time of the interviews, namely, *No Secrets* (DH, 2000). Consequently, practice responses with adults who self-neglect were often seen as residing in adult social care and with other statutory agencies, such as healthcare and housing. However, this could mean that strategic responsibility for

policy, procedure and practice in respect of adults who self-neglect could “float about a bit.” Moreover, it also meant that some local authorities and their LSABs had not given much attention to self-neglect as a strategic issue. However, other LSABs, and their sub-groups, had assumed responsibility for governance and policy development in this area. Working with adults who self-neglect was recognised to be a multi-agency issue, and locating strategic direction within LSABs meant that existing structures and partnership activity could be drawn on:

“... it’s also of interest to the safeguarding board because obviously it’s a multi-agency issue. It doesn’t sit with our procedures, but it sits with safeguarding ... in its broad umbrella remit.”

“In self-neglect policy, because it links so closely to safeguarding, the governance is the safeguarding board. That’s the place where it strategically is linked up. All those [relevant agencies] are on the board so again that’s the appropriate place for that to be done.”

One local authority had recognised the problem of where self-neglect sits strategically and operationally, and had used specialists to support protocol development and training, and had engaged two sub-groups of the LSAB – one to develop a training plan and one to produce information and guidance on mental capacity and self-neglect. The LSAB and its sub-groups had acted as a multi-agency forum for discussion and feedback. The risk otherwise was that self-neglect would not have been considered elsewhere.

Policy development was reported by some managers as being located in sub-groups responsible for quality assurance and/or policy and procedures. Such an approach, once again, was seen as giving institutional force to self-neglect being a multi-agency responsibility. Locating the development and signing off of self-neglect protocols, procedures and practice guidance within LSABs was a means to providing a framework for practice and for ensuring agency buy-in:

“The procedures are very much based on it being a multi-agency responsibility. It’s easier said than done, because people might nod their heads in the boardroom and say, ‘yes, we’ll sign up to that,’ but then it’s about getting proper engagement on the ground. Again that’s why it’s important to link it into the safeguarding process and procedures because that does bring people together ... that’s where you get people on board.”

“I think there’s a feel that there’s an authority behind safeguarding, you can put someone on a protection plan, everyone has to sign up and they have to do something.”

Such an approach was also seen as promoting accountability, even if this was a work in progress:

“The good thing is, going through the board there is a process there of holding people to account, so we’ve come back to, ‘where are you up to with self-neglect procedures, can you tell us how you’ve done that, how you’ve rolled that out in other agencies?’”

The LSAB was seen as offering an overarching governance structure within which self-neglect could nestle, thus obviating the need for a separate forum. Equally, this meant that an area of work that is stressful, challenging and complex for staff was given particular attention:

“Members of the board have all been fine with that. I think they’ve all taken an interest in self-neglect work because they know it impacts on their staff and in their organisations.”

If one reason for locating strategic development of self-neglect work within LSAB structures was that it was a multi-agency issue, another was the adult safeguarding remit of LSABs in respect of protecting people with and without capacity, while a third was recognition of how working with adults who self-neglect impacts on staff. Nonetheless, locating governance of self-neglect work within adult safeguarding structures continued to be a site of contest:

“I think generally ... people have varying views about whether self-neglect is a safeguarding issue or not. When people say to me, ‘going back to the definition, nobody’s harmed them. Why are you doing this under safeguarding?’ It can be pretty hard to justify it sometimes. That’s why people have gone different routes and there’s quite a lot of debate around that. Even when I go to [regional] meetings and this issue keeps coming up of self-neglect and some safeguarding leads are very clearly of the view, ‘no, it’s not adult safeguarding, nobody’s hurting them, nobody’s financially abusing them or anything, that’s fine,’ and people like me say in some cases I do think it needs to sit in that remit. In others I agree it can be managed in care management and there’s others that are just of the view that ‘it’s always safeguarding’.”

One manager was openly disappointed that the Care Act 2014 would not resolve the location of responsibility for self-neglect:

“We were hoping that [it] would give us a very clear steer and now it would appear that that’s not going to happen.”

Commissioning serious case reviews

Research has identified that at least some LSABs have commissioned SCRs where self-neglect has been a key cause of concern (Braye *et al*, 2013, in press a, b). Managers also acknowledged that LSABs were the authorising environment for determining whether an SCR would be commissioned. In some instances the commissioning of individual agency management reviews, specific criteria for which were unclear, was more ad hoc. The LSAB sometimes determined how a serious incident would be investigated and sometimes delegated decision making to agency managers.

A number of those interviewed were familiar with SCRs that had been commissioned by other LSABs and had used the reports in training in order to raise awareness of good practice, for example, concerning reviews of people holding personal budgets, support offered to carers and authoritative questioning of individuals about their situation. One manager thought that being able to “get hold of some cases of self-neglect would be really fantastic because staff need to see what happens in these cases”. As reported below, there was also evidence in the local authorities visited

that where LSABs had commissioned SCRs, the recommendations had been used to develop policy and practice.

Responsibility for policy development

Some local authorities, with their statutory partners, had developed policies and procedures for working with adults who self-neglect, underpinned by definitions of self-neglect, sometimes adding specific protocols on such topics as hoarding. Sometimes these policies, together with others on topics such as information sharing, had been developed across a number of local authorities, or indeed regionally, in recognition of the number of agencies – such as fire and rescue, ambulance trusts, the police and acute hospitals – that served a wide geographical area. Here, different approaches across local authority areas with respect to governance could create complications and delay, but a joint approach was also felt to facilitate agency engagement in adult safeguarding. In other instances, local authorities were not working to a definition of self-neglect and had yet to develop a strategy for working with adults who self-neglect: “I wouldn’t say we’ve got a strategy, I think we’re at a point where we’re starting to pull that together.”

However, agreeing policies across agencies did not necessarily guarantee across-the-board implementation, illustrating the need for LSABs to work continuously at ensuring multi-agency partnership working. As one manager observed when referring to an information-sharing protocol:

“That wasn’t robustly signed up by all of the agencies so it’s recently been rewritten by the policies and procedures sub-group and that’s going back as we speak through the Adult Safeguarding Board, as being the mechanism to share information.”

Two managers in particular were unsure of the distinction between policy, procedure, protocol and guidance, partly because of ongoing uncertainty or disagreement about where strategic development and oversight of self-neglect work should reside:

“In some ways I see it as a bit of guidance myself, because I feel like it should ... be in there as a piece of guidance under those safeguarding procedures. We didn’t really end up getting that agreed so it’s sitting as a procedure, which does make it end up sitting slightly separately really. I suppose you could say it comes under safeguarding policy, it’s an additional procedure under that, so that gets a bit technical.”

If managers are uncertain about the significance of what had been developed, it is questionable how practitioners will see its status in practice. The manager quoted above was also concerned about next steps, if this documentation about self-neglect was to prove meaningful. This links directly into training (covered below) and quality assurance. However, it also points back to the strategic location of, and responsibility for, self-neglect, in order to monitor implementation. Neither the allocation of responsibility nor quality assurance were straightforward, due to the ambiguity of the position that self-neglect should occupy, as the manager went on to observe:

“We don’t have a statutory lead to lead this; in safeguarding very clearly the local authority has a statutory duty.... With self-neglect we don’t, we’ve sort of taken it on in the absence of anyone else taking the lead with it, but when you look at the procedures, they very clearly say that the lead agency could be any of the other

organisations. Although the board has signed up to it, I'm not fully convinced that all the other organisations have totally taken on board what that actually means, and what they've signed up to."

"Yes the key is really going to be ensuring people are actually using it, and that somehow we are monitoring the quality of it. We do, for example, audits and safeguarding investigations, well this work won't be audited in that case because it sits outside of it.... I think with this you'd have to set up some sort of multi-agency audit process or something."

All of the local authorities visited housed safeguarding units or teams, which had responsibility for LSAB management and servicing, the provision of advice to staff, policy and procedure development, overseeing SCRs and management reviews, and quality assurance. In some instances, additionally, they worked directly with or reviewed progress with complex cases. While sometimes few in number, such specialist staff were taking a particular interest in self-neglect cases, for example, by developing tools and manuals for work in high-risks cases, or where risk and capacity assessments were particularly complex.

4.1.2 Building multi-agency cooperation

Some commonalities and some divergence were found in arrangements to promote inter-agency cooperation on self-neglect and in the experience of attempting to secure strategic agreement across a range of organisations. In working through this process, managers in adult social care and adult safeguarding sometimes looked enviously across to children's services where they believed that the multi-agency network at strategic level was already really engaged with safeguarding issues. On the adult side it felt "much more variable and less secure". The implementation of the Care Act 2014 may begin to change this picture as it places LSABs fully on a statutory footing and requires organisations to cooperate.

Perhaps an overall judgement would be that the picture of inter-agency communication and cooperation is improving, but that it remains variable, at strategic and operational levels, as other research on adult safeguarding has also found, for example, with healthcare commissioners and providers (Braye *et al*, 2011b; Cornish and Preston-Shoot, 2013). Six sub-themes emerged in relation to multi-agency cooperation: 'getting sign-up', 'locating self-neglect within overarching multi-agency structures', 'systems used to facilitate multi-agency working', 'different perspectives on ethical dilemmas', 'assigning lead responsibility' and 'how particular agencies are participating'.

Getting sign-up

What clearly emerged is that building and maintaining multi-agency partnerships required constant attention and focus. Building and maintaining relationships could be quite difficult, time-consuming and challenging. For example,

"The police are coming more on board, very much more on board. Again, that took a great deal of dialogue with them, to explain why we needed to work together on some of these cases."

Locating self-neglect within overarching multi-agency structures

One recurring focus was the search for a location for self-neglect, either within or beyond adult safeguarding. In terms of building multi-agency collaboration at a strategic level, the value of locating this initiative within adult safeguarding was that it facilitated both strategic engagement and buy-in, and operational familiarity with inter-agency working. Most managers commented in some way that a lead and subsequent oversight from the LSAB was crucial in devising an effective multi-agency approach for intervention in cases of self-neglect, managing the risks involved efficiently and ensuring coordinated action operationally. Agreeing policies, procedures and protocols in the LSAB tied agencies into processes for practitioners and operational managers to follow. Such agreements also cut across what could become a sterile debate about whether self-neglect was to be seen as part of adult safeguarding. Thus:

“Every agency has signed up to the policy; sometimes what we were finding prior to that, we would invite people like environmental health and maybe [they’re] reluctant to come but it’s reminding them ‘you have signed up to the protocol.’ So it’s really once you have everyone together ... each agency can put their input and then devise some sort of plan.”

“The other thing is, the closer it is to safeguarding, the higher up people’s agenda it tends to be. If you say ‘self-neglect’, we’ve already talked about health colleagues perhaps looking at it and going, ‘we don’t have anything to do with that.’”

Systems used to facilitate multi-agency working

Some of the local authorities visited had agreed at board level a VARM approach through which to secure multi-agency cooperation operationally. Once again, LSAB endorsement was perceived to lend authority and credibility to this way of working with adults who self-neglect:

“If you are struggling as a health or a social care agency, to engage the necessary partners, bring it into VARM. Because that’s been signed up to by the board and it’s much harder then for partners to refuse to be involved. If they do refuse to be involved, we would be happy to try and encourage their involvement.”

Working strategically to agree such an operational system brought benefits in terms of efficient use of resources, a challenge to threshold bouncing and silo working, and more coordinated and effective interventions. This process, which resulted in the adoption of a VARM approach, is captured by one manager as follows:

“We were hurling all these resources at these people and the police had disengaged, the ambulance service had disengaged. They couldn’t get through the door, the mental health services at all, there appeared to be nobody else that wanted to pick anything up at all and even when we had really genuine concerns about some of these individuals around their mental health and their emotional state, trying to get them the right sort of support was nigh on impossible really. We’ve found that [the risk management approach] has been really helpful, in terms of trying to get a clear

picture of what it is that people are doing and being clear about which organisation has responsibility for what and at what point they'll pick it up. And through that process ... we don't get a difficulty now, if a social worker rings the police, we don't get the run-around ... for this handful of individuals, the police have a nominated officer that we can link in directly with; they come to the formulation meetings, so it works quite well."

Different perspectives on ethical dilemmas

Nonetheless, building multi-agency systems could be a challenge because of the ethical dilemmas involved when working with adults who self-neglect. Managers referred frequently to concerns about how to balance respect for an individual's private and family life, when they have capacity to take particular decisions, with a duty of care. Unsurprisingly, differing expectations relating to confidentiality and consent also emerged as potential obstacles to securing both strategic and operational collaboration, and ethical challenges were debated in the LSAB as part of seeking agreement through a procedure or protocol on a joint approach:

"Getting multi-agency agreement can be a challenge because of different responses to the ethical challenges involved."

"I would say we still have more work to do especially with GPs, around communication, because GPs will very often refer back to patient confidentiality: 'We've got a relationship with this person, we don't want that to break down because we've talked to you about these problems'."

"On consent we had long discussions with the police, to get them to actually ask for consent on the forms that they submit to us, so that we have an agreement to contact, but particularly in cases where there is no consent, it's important then that you have your health involved or nursing involved or somebody that can actually get through the door. I think it's also important that actually if someone in the community, a professional from another agency or whatever, if somebody is bringing information to us that they're concerned enough to refer to us, we need to take that seriously as well so we won't just be turning stuff away on the basis of 'we haven't spoken to this person and gained consent.'"

Assigning lead responsibility

A wide variety of agencies were involved alongside adult social care in building collaboration in respect of self-neglect, including health commissioners and providers, mental health, learning disability, environmental health, police, the fire service and housing. Managers saw these as key organisations "because self-neglect involves disengagement and affects people receiving healthcare treatments and mental health services" and "if people present with hoarding, we are also thinking about fire risk and that can involve people who can have alcohol and mental health issues ... that's why we try to pull in these services because they are quite relevant to the risks." Indeed, self-neglect SCRs (Braye *et al*, in press a, b) illustrate the wide range of agencies potentially involved, and the key role they may have in getting across the threshold and in escalating concerns about risk. Unsurprisingly, therefore, one preoccupation was the development of policies on risk assessment

and on engaging people who are hard to reach. One local authority had developed the concept of key roles to the point of distinguishing between, on the one hand, those agencies and professionals who are at the front line of recognising cases of self-neglect and, on the other, those who could take the lead in any subsequent assessment and intervention. This distinction was then informing a training strategy, with different courses being offered, tailored to workers' location and likely role.

"It's not clearly one organisation taking a lead, we were really keen that it wasn't just going to be ... everyone just going, 'oh well, I've sorted someone I think might be self-neglecting, I've just got to send them referrals.' ... We divided it into organisations, which were more on the lines of the emergency-type organisation that might be the ones who might spot it. So that could be any organisations at all, and that would include fire, police and ambulance.... Then the organisations that would lead would be the local authority and the three local health trusts.... Oh, and then within the local authority we've divided that into housing particularly being one of our key agencies that could be the lead."

Clearly, then, for the managers interviewed, self-neglect was a multi-agency responsibility, with adult safeguarding systems holding the ring both strategically and operationally to ensure that agencies really work together and to give agreed procedures and protocols "institutional force."

How particular agencies are participating

Managers shared accounts of strong strategic links with such agencies as housing and environmental health, which had encouraged operational staff to make referrals and to escalate concerns. Put another way, investment in building multi-agency collaboration at a strategic level was generating operational benefits in terms of agencies working together to safeguard and promote people's wellbeing.

"We've established very, very good relationships with fire and rescue and we've got [an alert form] which the fire brigade will fill out ... they're very, very engaged and we've had a number of case conferences where they've come along to discuss specific concerns.... So that relationship's very robust and the fire service also sit on the Adult Safeguarding Board, so even at a strategic level, they're represented."

"Very often now, the police will accept responsibility for doing welfare visits on people who we feel are neglecting ... making sure that people are calling in, to make sure that person's okay and that they're not being targeted. So we've had some good pieces of work."

"Housing colleagues are very, very engaged. We will always try and work with housing to see whether there's a preventative option because the last thing we want is to evict somebody and the problem just to be moved somewhere else."

However, building collaborative relationships was not all plain sailing. Some managers reported that less progress had been made with voluntary agencies. They attributed this to people tending to veer towards commissioned services when there were concerns because of anxiety about the risks involved. However, there were

examples of where voluntary sector agencies had been engaged at a strategic level, which had resulted in the development and provision of services for people who did not meet the adult social care eligibility criteria but where there were elements of self-neglect. Similarly, there were accounts of challenges engaging with healthcare colleagues, including GPs, and in establishing safeguarding investigations as not just a local authority responsibility. This issue was also prominent where health and social care were moving towards integrated services.

“One thing that we’re struggling with at the moment is within the integrated teams. Health colleagues cannot see the need to train up health staff to be investigators of safeguarding concerns because they’re saying, ‘it’s the key responsibility of the local authority, why would we train our staff up? If we identify a safeguarding concern or self-neglect, we’ll tell you about it and you’ll investigate it.’”

Personalities and pre-established relationships could help to facilitate multi-agency working at strategic and operational levels.

“For the first time we’ve got a lead GP for learning disabilities which we’ve not had before and she’s brilliant, she’s just about to take on the lead for adult safeguarding, very proactive, very clued in, really enthusiastic and really quite committed....”

Vignette: David

Here there was regular communication between the wide range of professionals involved, monitoring and containing a situation until a crisis provided the opportunity to bring about change. Recognising the impact of personal circumstances and life history enabled those involved to work at a pace that the service user could tolerate.

David, a man in his eighties in very poor health, was a survivor of the Holocaust and had always lived a very independent life. Concerns had arisen because of the severely neglected state of his home, lack of heating, and rotting food piled up, but he would tolerate no discussion of this or of the need for personal care. The social worker kept visiting, getting to know David and to understand how his previous experiences contributed to his way of life; after many months he had reluctantly accepted a basic care package and visits from the district nurse, but would often not open the door when they called.

The practitioners in primary health and social care operated as a team, regularly communicating with each other, enabling the situation to be monitored holistically by whoever had last seen David; when the state of the house became a severe risk to health, cleaning was enforced by environmental health, with the backing of the other agencies, but still David had no interest in changing the way he lived. Then a severe health crisis meant that he became more open to discussing his changing needs; after sensitive negotiation by his social worker, engaging the trust gained over a long period of building a relationship on David’s terms, he agreed to respite care and then to a move into supported housing.

4.1.3 Configuring referral pathways

Strategic development included a focus on referral pathways, how cases of self-neglect found their way into local authority settings, and subsequently on the management of the work referred. This was one aspect of agreeing a multi-agency approach to self-neglect work. This section explores the reasons why this sometimes proved to be complicated, what approaches were taken to agreeing referral pathways, challenges to effective inter-agency working, and what was done to ensure that referral pathways – once agreed – were implemented.

Without an agreed approach between partners, concern was expressed that a variety of routes into a local authority – adult social care, adult safeguarding, mental health or learning disability specialist teams – could lead to inconsistency of response. This might then subsequently deter referrers if they felt that the work was not taken forward and that possible options for working with the case were not considered. Equally, individual agency reviews or SCRs commissioned by LSABs had shown that healthcare and social care staff had not known where to refer or to escalate concerns, and how to put self-neglect cases on the agenda. Alternatively, they had made referrals but not followed them up. This had prompted the local authorities concerned to bring local agencies, including the voluntary sector, together to agree pathways. This failure to refer or to follow up on referrals was a finding echoed in research into self-neglect SCRs (Braye *et al*, 2013, in press a, b).

Managers reported that there were a number of issues to consider in agreeing referral pathways and subsequent management of the work. For example, referral pathways could become more complex to agree strategically because a self-neglect case might also involve neglect by another person, which would be seen in safeguarding terms, mirroring findings in the above-mentioned research, which found several instances where an individual who was self-neglecting was living in a household where, whether by omission or commission, they were also being abused or neglected by other family members or carers. As one manager commented, who had seen just such an SCR in their area:

“Sometimes more than one person [in a household] is self-neglecting or sometimes one person is self-neglecting and the other is neglectful, either by omission or commission. I think that adds an interesting additional dynamic, because we’re used to talking about self-neglect cases as if there’s just one individual. I think potentially that case could have come into safeguarding and that would have produced a multi-agency response.... That didn’t happen.”

No single, typical pathway for referrals emerged from the interviews. Rather, what was agreed between partner agencies depended on a number of factors, not least the organisation of local authority adult social care and adult safeguarding teams, and the degree to which healthcare and adult social care staff were co-located. However, agreement about pathways afforded a structured approach that people could see and follow. Thus, in a local authority without a formally established adult safeguarding team, all self-neglect referrals were mainstreamed, with allocation to specific workers depending on the complexity of the case. Triage was undertaken by a senior social worker who would decide on the immediate level of risk and where best the work should be continued. Selecting the most appropriate team would depend on an individual’s presentation and whether mental health and/or learning

disability issues were highlighted. This meant that engagement with self-neglect was potentially very wide among all teams, with implications for training. Equally, allocation was not unproblematic because of 'behind the scene negotiations' around workloads and thresholds set by specialist mental health and learning disability teams. Thus, there was a feeling that "this is quite untested for self-neglect and I think it is going to be tricky, just as it has been for safeguarding."

In another authority, integration of healthcare and social care staff at locality level and within specialist teams, such as for dementia patients, was felt to promote effective handling of referrals.

"Focus is on best outcomes for the individual and on removing barriers to organisational interaction. Health and social care staff attend each other's team meetings and multi-disciplinary attendance at GP meetings. Social care staff are located in hospital settings. Some teams have shared offices and joint triage of referrals to enable joint decisions on responses to referrals. Across all agencies, there is a philosophy of working together, trust and knowing each other well, a belief that provision can be seamless."

In some other local authorities, referrals were made initially into care management, with subsequent referral onto adult safeguarding specialists if multi-agency collaboration needed to be reinforced.

"When it's got to the point where people can't manage it under care management – and we strongly encourage people to try in the first instance to work with people under care management – if it can't, people then generally refer it on through safeguarding. I think people tend to do that because there's an expectation that multi-agency buy-in will be gathered through a strategy meeting and a case conference and care management doesn't always get all of those people around the table."

Similarly, the route that referrals would take after receipt by the local authority could be determined by their complexity. Here the defining consideration was flexibility of response to meet the needs and risks identified.

"It depends on the nature of what the self-neglect is... If it's deemed as just one agency that needs to be looking at that because it is around self-neglect and there is no criminal element to that, then the good thing is [the police] still send that in and it will be picked up initially by our adult safeguarding team, who will then direct it to where it's most appropriate. And that works well."

Flexibility of response could mean considering the nature of the case and the needs and views expressed by the person who uses services. What might determine the allocation of the case could be finding a worker who could make contact and engage someone who had been hard to reach. Or the gender of an allocated worker could be the significant factor. Equally, a service user might find it more palatable to engage with one agency, such as healthcare, as opposed to another, such as social services. Consideration needed to be given to who the best person, or best organisation, might be to do the work. Accordingly, threshold criteria had to be treated flexibly rather than rigidly enforced. Put another way:

“Every individual is different so the task is finding the right solution at the right time to keep that individual safe. There is a cost to commissioning services and to practitioner input but one cannot say no.”

This might mean managers drawing on their professional instinct when considering that “nothing simple comes through our doors” and thinking about the best approach to meeting an individual’s needs on the basis of the evidence within the referral. This might entail drawing on knowledge of what might lie behind an individual’s self-neglect when thinking through allocation to a mental health team. It might mean deferring to another agency’s definition.

For some managers, then, there were no typical referral pathways; self-neglect was a difficult and special case.

“Say somebody comes through to the hospital, they’d be picked up through self-neglect, their gangrenous leg, maybe diabetes, neglect of insulin and so on, those things begin to pop up in primary care or secondary care and then it gets referred into us as the lead agency, that’s always been the pattern. When those referrals are made, people would be wondering, is it a safeguarding risk or something along those lines?”

As other researchers have found when investigating how need is identified and then communicated between agencies (Cestari *et al*, 2006; Charles and Manthorpe, 2007), there was a perception that referrers might inflate levels of need or concern in order to ensure that adult safeguarding or adult social care accept the case.

“Yes, sometimes there’s a concern and they bring it into safeguarding to see if it meets the threshold for an investigator to go out. If that investigator then wants to convene a meeting, they’d say ‘I’ve got a bit of a problem,’ and then within that they’ll spill in at least half a dozen things in order to get the threshold up ... dress it up in order for us to take it.”

One feature of inter-agency work, and not just in cases of adults who self-neglect, is threshold bouncing and a silo approach where the person’s needs are not considered holistically because each agency or professional is focusing on their specific role. Self-neglect SCRs have been critical because this results in no one agency accepting responsibility for a case, or in individual agencies focusing only on isolated parts of the picture and failing to engage with the full scope and breadth of the individual’s situation and needs (Braye *et al*, 2013, in press a, b). This recognition also requires a referral pathway that is flexible and responsive to individual need, as well as agreeing the practical and definitional interface between adult safeguarding and those agencies working with individuals who self-neglect.

One downside, however, to having a variety of referral pathways was that no one individual or team had a complete oversight of self-neglect being undertaken by the local authority and its partner agencies. Although this challenge could in theory be overcome with data collection on which cases had elements of self-neglect, the managers interviewed were reporting their impressions as much as the actual outcome of what had been agreed for the management of referrals by LSABs.

“I think people commonly refer to the adult safeguarding policy and procedures. What you have to bear in mind is that I only see the ones that get through the safeguarding because I don’t manage the social work teams.”

Underlying negotiation about referral patterns was often a concern to avoid adult social care and/or adult safeguarding becoming the default location for cases of self-neglect.

“What we put in the guidance is that the lead agency would be the one that pulls together the initial multi-agency meeting, so that would be your immediate forum about pulling everyone together and they have to take that lead in then sending out any minutes or agreed actions. What we were trying to cut down on is ... everything referred into the local authority.”

One local authority, learning from serious incidents and from cases being brought to a ‘high-risk’ panel, had worked with the fire and rescue service on referral processes. A checklist had been developed about what to look for on a home visit in terms of risks, including fire, and how to make referrals based on observed concerns into fire and rescue, providing an example of referrals going to another agency rather than concern simply being escalated to the local authority. Inter-agency cooperation had been assisted by the making of a protocol.

Having agreed how referrals were to be made, the next stage was to ensure multi-agency involvement in subsequent work. This, too, was taken forward in a number of ways. Those local authorities that, with their partner agencies, had adopted a VARM system used this process to monitor the outcome of referrals, wherever within the health and social care system the work was being led.

“We each have a number of VARM cases that we keep an eye on. So you’ll be familiar that we’ve got a risk matrix, and there’s an expectation that people should hold meetings within X number of days, depending on the risk score. The business support staff will keep an eye on that, and if we haven’t received notes or an update ... the business support staff will chase the workers. If they fail to get a response, they will pass that to the nominated manager, who will then make an approach to the practitioner. If that fails to be successful, that is escalated to the service manager. If that still fails to be successful, it is escalated to head of service, because these are high-risk cases, and they need to have a high level of scrutiny.”

This aptly captures the complexities, risks and challenges that such cases present. Other local authorities managed this complexity through case conferences designed to promote information sharing, multi-agency panels that focused on particularly complex cases, and group meetings where scenarios could be shared for learning and peer supervision. Support for staff and the involvement of senior managers to oversee intervention in very complex cases emerge from these examples.

“We often recommend multi-disciplinary meetings with self-neglect cases that don’t meet the threshold for safeguarding and we do try to engage with health and housing and anybody else that might be

involved. Our suggestion would be to find a key worker that actually can make contact, not necessarily the social worker, care manager, OT [occupational therapist], not necessarily someone from the community team, just a key worker that can get across the threshold."

"Where that practitioner-level response to self-neglect has failed to make any change, and actually the risks continue to escalate, that would go up to the vulnerable adults panel [where] there are senior managers sat round the table, who in effect can be more creative in terms of use of budget.... So the vulnerable adults panel has got enough seniority to be able to come up with more flexible solutions."

"We did think that it was best to set up some sort of forum where we could discuss some of these complex cases, many of which involve self-neglect, hoarding and service refusals, and ... we got the buy-in from a number of key agencies, including the fire brigade, adult social services and mental health. We have the head of psychology from the learning difficulties service, a drug and alcohol service worker, the voluntary sector, and a dotted line to the police. If we do need to seek legal we can do that. The panel isn't there to make decisions, it's there to give advice, it's there to give suggestions. Sometimes we have had situations where there is absolutely nothing else that could have done and it was just validating."

Such a panel for multi-agency scrutiny and discussion is also able to recommend a different strategy and to help facilitate this in terms of engaging a different network of agencies. This can open up a new pathway for a particular case, with the panel being quite instrumental in moving things on.

"What's really helpful is the practitioner comes with a case. They fill in a form prior, they tell us what the risk issues are, they tell us what interventions they have tried, what hasn't worked, what worked. They also give us an idea of what they're hoping for, what they're trying to achieve if everything is an ideal world. The panel members have a chance to look at that beforehand, so they can check ... is this person known to our service ... if environmental health can think, well actually this case might be something we can help with, they can exchange information there and then, give contact details.... Mental health can do the same, adult social care can do the same. If it's a housing case I can take it away and say, 'Do you know what, I think we need to get this allocated; this is the housing officer, can we set up a joint visit?' and that's how things move forward."

Another manager stressed the value of case conferences in facilitating inter-agency communication and supporting staff to draw on available guidance and expertise in different organisations. For best value from such meetings, the manager recognised the importance of helping the practitioner to be clear about what they were trying to achieve by bringing different professionals together, about their risk assessment and

about the support they were seeking. This manager, and a colleague, also saw such conferences as a way of containing staff anxiety.

"I say these days, 'have you had a multi-professional case conference? You've got safeguarding, you've got our protocol for self-neglect framework, so almost any case that's challenging you, if you get to the point where you're all thinking 'what on earth do we do next?' why don't you have a multi professional case conference?' One of the things that is a real feature in this work, is the level of anxiety it generates for managers, for workers.... Using the vehicle of a case conference is to spread the decision making and get a multi-disciplinary decision."

Thus, building panels and case conferences into strategic agreements about how to work with cases of self-neglect was motivated by the recognised need to support practitioners and agencies who would otherwise be "struggling on alone" and, through access to other perspectives from staff less involved in the day-to-day experience of the situation, to explore different approaches. They provided "another set of eyes", including specialist advice from legal, housing and public health specialists, that could make a difference. Carefully recorded, they also met the accountability imperative.

4.1.4 Turning strategic commitments into frontline practice

Arriving at strategic commitments about referral paths and multi-agency cooperation is one thing; ensuring that they are understood and implemented by practitioners and managers is quite another. Finding a strategic home for self-neglect policy and practice, developing protocols, procedures and guidance, and commissioning reviews of practice is, similarly, only half the story at best; the lessons for good practice have to be effectively disseminated and their outcomes tracked. A variety of mechanisms for this, and concerns about their effectiveness, were uncovered in interviews with managers. They are structured here under four sub-themes: 'training', 'guidance', 'approaches to learning and service development' and 'access to specialists'.

Additionally, it should be noted that although the focus was predominantly on workforce development, in one local authority particular emphasis was also given to developing a multi-agency appreciation of the importance of developing public awareness of self-neglect through information campaigns and community discussion forums. Thus:

"I think it's quite important that we should be raising public awareness and there is a lot of that sort of community spirit, of not noticing that your neighbour's got 15 milk bottles because the milkman doesn't deliver anymore, or the curtains haven't twitched in the last month or ... and why that person hasn't been seen for a long time."

Training

In relation to training, the interviews touched on the challenge of making sure that it transferred into practice, what training existed that had relevance to self-neglect, and the limits to what some training could achieve. Joint training and training in mental capacity came in for special mention.

Some managers recognised the need for training if the guidance on self-neglect was going to achieve anything. The move to proceduralise self-neglect work, often in response to complex cases and SCRs, is interesting, if only because the same SCRs often also conclude that staff don't use or follow the guidance they already have (Braye *et al*, in press a, b). Indeed, research conducted shortly after implementation of the *No Secrets* statutory guidance in England also concluded that practitioners were often only likely to turn to guidance and procedures when they had exhausted their practice wisdom (Preston-Shoot and Wigley, 2002). Here is a useful recognition that much more is needed:

"What they've signed up to is that their staff need to be competent, capable and understanding of the procedures well enough to be able to take the lead role in following those procedures, which would be putting together a multi-agency meeting and all that. At this stage I'm starting to go to some of the steering groups and some of the other organisations, particularly the health organisations, to say, 'OK, these have been signed off. Now how within the organisation are you going to make people aware of them, and make sure people have the training?'"

The training offer has to be systematic if its reach and outcomes are not to be undermined by people dipping in and out. Thus, in one local authority area, the launch of the procedures was to be followed by training specifically around self-neglect, "to build that knowledge and expertise up." There was a perception that "it's not something you come across on your social work training particularly."

Another imperative behind recognition of the need for training specifically on self-neglect was that "staff, for many years, have not known what to do with it", or they have thought that, "it is not my job if this person does not want to engage." SCRs commissioned by LSABs had engendered a sense of challenge to staff, a questioning of practice, which had led to requests for skill development. Thus, some managers were recognising an issue around staff confidence and were proposing to offer workshop-style training, involving colleagues from across agencies, and team meeting discussions. The purpose of both was to disseminate procedures and to clarify what was recommended in cases of adults who self-neglect, "because some of our team leaders really struggle and some of the workers really struggle with it as well."

Examples were found of training events, such as commissioned conference presentations, which had focused specifically on self-neglect. These had been experienced as "incredibly helpful". Annual conferences were particularly popular, with wide attendance, entailing "a positive process for engaging partner agencies". Where local authorities had adopted a VARM system, training on this procedure included a very clear focus on self-neglect alongside interviewing and investigative skills.

"... what we do is obviously, we're talking about what self-neglect is, we give them some examples in terms of serious case reviews ... and then we say this is the process. So it's ... this is the context, this is who we're talking about, these are some of the frustrations and the worries, and this is what we've got in place."

“... understanding it’s not about judging how someone lives, it’s trying to understand why they live how they live.... What I try to get people to think about ... to think differently, is that I challenge their capacity assessments in the first instance and think about the Mental Capacity Act.”

Other local authorities had organised specific training courses on hoarding, looking at people’s responses to self-neglect, who to refer to, and when such cases might become a safeguarding issue. Still others had arranged awareness workshops in order to disseminate guidance, signed off by the LSAB, on working with adults who self-neglect. Here, some managers had found that the impact of training was more effective if it had been interactive and built around actual case examples. Some interviewees gave examples of what self-neglect training ought to cover, such as the practice steps to take and the legislation that should be considered, or that service refusal should not be taken as an invitation to “just go away and never do anything again ... because of the risks involved.”

More often, what was being offered to practitioners and their managers was a training programme that focused on mental capacity, community care assessment skills, safeguarding and mental health “but without much coverage, if any, of self-neglect.” “We’re quite robust I think in the training [but] I have to say that the training doesn’t yet focus enough on self-neglect. It doesn’t.” Another manager acknowledged that, “none of our training really touches in any significant way on self-neglect.” It was not unusual, therefore, for managers to hear pleas for more training and to receive reports that the training that was offered on working with adults who self-neglect was routinely over-subscribed.

“I think we do need more training. I think we do need to look more into neglect and risk. I don’t think there’s sufficient training around that, to be honest. I think we do talk about it a lot with our workforce development and that’s the sort of thing that only recently I’ve been talking to them about, looking at risk.”

“... if we use the attendance as evidence that people being interested, we’re always over-subscribed, always very, very popular and a lot of people wanting to know more about it now.”

Nonetheless, some concerns were expressed about the training offer. One was that knowledge and skills acquired through training might decay if the learning was not routinely being applied. This anxiety was especially prominent in smaller authorities where, based on population demographics, complex cases of mental capacity and/or self-neglect might arise less frequently. Indeed, the phenomenon of knowledge decay when not routinely being used has been recognised as one possible outcome of professional education (Preston-Shoot and McKimm, 2012). Another concern was that specific training self-neglect was failing to reach certain parts of the health and social care workforce, such as healthcare professionals and private providers of home care. As one manager reflected, the “pattern was uneven in terms of what was offered and who was reached.” A third was that training “does not touch the sides” and that case-based discussions in small groups would be more effective in promoting learning through exploration and reflection.

Local authorities with a tradition of working closely with neighbouring councils had attempted to provide specific training across boundaries, not always successfully. Securing agreement on joint policies and procedures was one challenge, with examples in the shape of protocols and guidance manuals where this had been achieved referred to earlier in this report; joint training was another:

“Every area wants to deliver it in its own way and every organisation is going to want to deliver it in its own way.”

Another training-related question emerges from concerns about understanding and implementation of the Mental Capacity Act 2005, where research and SCR findings suggest that understanding of what is necessary in capacity assessments is not distributed across all staff who need to know. Concerns were expressed that mental capacity training was not uniformly good, and that challenges were posed by the numbers and turnover of staff requiring it.

“We were quite slow to get people to really understand what the Mental Capacity Act meant to them and it is absolutely constant training of providers ... we have such a huge turnover in staff in the provider sector, you can train everybody one day and the next day you....”

Some managers commented specifically on low satisfaction with the standards of capacity assessments and best interest decisions, and saw knowledge and skills in this area as feeding into self-neglect training. One manager was unequivocal:

“It has to. We have a competency framework here, which initially was around safeguarding. So it’s a process through which we regularly do a competency audit of staff practice to ensure that they’re competent. We do a similar process around MCA [Mental Capacity Act] practice now, it’s really good and staff like it as well so it’s a good tool. I think we’re going to roll that out over a whole range of other areas and think self-neglect will be one of those in the future.”

In response to whether this manager saw self-neglect training as being a way of delivering mental capacity training or whether it should be separate, they said: “A bit of both I think, it’s separate and linked. Mental capacity has to be intrinsic to this as well, doesn’t it?”

Vignette: Practitioners reflect on training

Amy was a qualified social worker who had worked closely with a number of people showing self-neglect; here she reflects on the impact training has had on her practice. “I had some very illuminating, eye-opening training recently about hoarding specifically; in fact, it was OCD [obsessive compulsive disorder] including hoarding, it was about hoarding as a specific behaviour rather than self-neglect generally. I have to say that that caused for me a big change in my practice, as social workers here and maybe elsewhere, we were doing it wrong actually, very specifically we were ... I think in response maybe to the pressure situations like hospital discharge ... we were colluding, enforcing a big clean or something and not seeing it as a coping mechanism that if you remove then there's no coping mechanism for that individual. So the training has made a big impact on my approach to those situations at the quite extreme end of the spectrum”.

Malcolm spoke about combining his own curiosity about self-neglect with learning on the job: “I've done quite a lot of reading around self-neglect because of my role in safeguarding, and I've been to various forums around self-neglect as well in the safeguarding context. I think really the most valuable things that are learned, are actually on the job from my clients, seeing what particular things they respond to and then remember it for the next one.”

Guidance

Managers spoke about the reasons why guidance was necessary, the priorities that had emerged in each authority in relation to its development, the challenges in ensuring it was followed, and the balance to be found between adequacy and excess.

Some local authorities had not, as yet, developed specific policies with respect to adults who self-neglect. Others had developed or were beginning to write protocols either on self-neglect generally and/or on specific manifestations, such as hoarding. These were sometimes very detailed and extensive, including coverage of all the legal rules available to different partner agencies such as housing, utility companies and environmental health. They were seen as providing a structure for multi-agency working and for presenting practice within legal settings, where “you can say to people, you have signed up to this.”

“Safeguarding issues around self-neglect, when the person has capacity, throw up conundrums. Now I've picked up a couple of cases recently, where local authorities have gone to court, where capacitated adults are considered to be vulnerable and then the courts with their inherent right of jurisdiction, will give an order. And again, what colleagues have told me within the region is that the documentation would be their own safeguarding policies and procedures, with the strategy meetings, the documentation of that, that would go as a bundle to the courts ... I say to people if you're recording, it's got to be good enough to present an audit trail.”

Continuing a theme, safeguarding services were seen as “coming into play in terms of trying to put together policies and procedures around the management of self-neglect because it has not been generated from anywhere else.” The motivation was for safeguarding teams and LSABs to “signpost it” even where it was then “to be

seen and managed as a core care management or social work function to look at and manage people who are self-neglecting.”

Different authorities were preoccupied by different priorities for the development and implementation of guidance. For example, one authority was concerned about the quality of risk assessments with people refusing services, and was responding by developing a risk management protocol.

“... what we’ve not been very good about, but we are now getting to grips with, is risk assessment. I don’t think risk assessment has been detailed enough within care planning for individuals who don’t want to engage.”

For some others it was agreeing a definition of self-neglect and a statement of good practice, sometimes drawing on work that had been published by other LSABs, because they had found that self-neglect was variously understood by the professionals involved and not always accepted as part of their core business.

“It doesn’t appear to me that there is [a definition of self-neglect]. I think that there’s generally a not great understanding of the management of self-neglect. It’s managed differently across the teams. It’s seen as a bit of a core business, certainly within the CMHT [community mental health team] ... they’re managing quite a lot of self-neglect issues in association to mental health problems and CPA ... it’s managed in that process there. I think within the wider community teams, there’s a little bit of lack of clarity I think about the role and responsibility....”

A variety of definitions were being evolved, some based on a published scoping study (Braye *et al*, 2011a). One manager defined self-neglect as follows:

“We class self-neglect as people who are difficult to engage with, people that may or may not lack capacity ... it was essentially people who were in a difficult circumstance; where neglect appears it’s not something that’s done by a third party, so if it appears that they were neglecting themselves or not engaging with services that would bring out benefits for them, that was the target audience for our piece of work.”

Generally it was recognised that self-neglect could encompass both neglect of one’s environment, such as in hoarding, and neglect of self, with elements of risk. It was recognised that it would be others who judged the situation to be a problem rather than the individual themselves – a housing officer reporting a tenant whose accommodation was “in quite a state” or a social worker trying to complete an assessment where the individual concerned was refusing to accept adult social care involvement. Both the search for a definition and any subsequent attempt at intervention were complicated by awareness that there is not necessarily an underlying, objectively definable thing called ‘self-neglect’, and that it is rather a matter of judgement about the nature of a situation. There was some variation in terms of whether adults without capacity were included in the definition. Sometimes this was discussed at a general level, but occasionally managers drilled down into the distinction between decisional and executive capacity. There was also some disappointment that the DH had not taken the opportunity presented by the Care Act

2014 to define self-neglect, outline its relationship with adult safeguarding and state benchmarks of good practice. Thus:

“I think the other challenge is it’s lack of detailed guidance from the Department of Health on what good practice looks like in these cases, because what might look very good practice to me, you might go to another local authority next week and see something else and think ‘in fact, that was much better’. We’ve got nothing to benchmark ourselves against at the moment so you’re almost working in isolation.”

The rationale for developing guidance was related to the “significant risks” that could be present in self-neglect cases. Such cases required “judgement calls” from practitioners, including knowing when to escalate when the risks were high. Guidance needed to acknowledge how slippery the concept of self-neglect could feel, and to embed levels of risk into practice in order to make any definition of self-neglect operationally useful. Once again, behind the imperative to develop guidance was recognition of how “very, very powerless” workers could feel when faced with individuals at serious risk, but where the legal framework was acknowledging their capacity to decide, to “make unwise decisions”. Guidance was designed to place their practice within a framework, for example, when working with people with fluctuating capacity who are in need but will not engage, that would help them to “feel safe by operating in a structured way.”

However, the activity of developing guidance was sometimes accompanied with concerns about ultimately whether it would be useful and/or followed. For instance, two interviewees were concerned that the impact of guidance was dependent on individual managers and teams – “what they do with it, it is up to them really.” Others were concerned to ensure that the guidance was practical and simple to use, focusing on “when those situations arise, this is how you need to think about it and this is how you need to work”, without over-promising solutions.

“One of the problems often with the self-neglect cases is all those things have been considered and they’ve come out to be of no use, no reason to use them and then you’re left with nothing.”

Some managers who were developing procedures and guidance were concerned about the length and depth of exploration of possible legal options, and how to strike the balance between highlighting legal mandates and foregrounding ethical or practice wisdom mandates.

“We debated that in the safeguarding [guidance] though, how useful that related legal guidance is in there, because I don’t know how much people really look at it. I suppose we could put something more in [to our self-neglect guidance] about legal remedies.”

“There’s various different legal issues there, but I think it was trying to get people away from just thinking what can we do legally? To get people to think a bit more about actually how do we build that relationship?”

Notwithstanding reservations and concerns expressed about the accessibility and active use of guidance, some managers were working on tools for practice and the management of practice. Thus, one manager was developing a best interests tool to

help to focus attention on that aspect of the Mental Capacity Act 2005. It was being designed to contain practical steps as well as to pinpoint the principles underpinning the legislation and to place the person who uses services at the heart of the process. Another manager and a practice development colleague were developing a high-risk manual. The manual was being developed to accompany the creation of a high-risk panel to which cases of service refusal, including those involving self-neglect and hoarding, could be taken. Once again, there was concern about how much and what type of information to include:

"We are incorporating quite a lot of information, although not too much, we don't want it to be too wordy, we want it to be a working document that practitioners can pick up and find very useful – useful information about who to contact, which team is best to contact, what can they offer clients in this situation... We've talked about self-neglect. We've defined what high risk in our context would mean. So we're talking about people who would hoard, we're talking about self-neglect, service refusers. So we've given a bit of information about people who would fall into that category, we've talked about how they can refer to the panel, we've talked about who are the members on the panel, what the panel does, and we're talking a bit about each service, who the service representatives are, what each service can offer, who the contact person would be or how to make a referral to that service. I think we're also including a glossary of common terms and acronyms that people might find quite useful from different services."

Approaches to learning and service improvement

Here managers spoke about specialist panels, audit, conferences, case discussion meetings and reflective groups as useful approaches to facilitating learning about self-neglect.

Access to specialist panels was one approach taken to reducing worker stress and isolation and supporting practitioners and operational managers to navigate through the complexities of self-neglect cases. Examples were found of self-neglect panels and high-risk panels.

"I think having the high-risk panel has really helped and also talking with some of my colleague managers to say look, you need to be careful that they're not asking them [social care staff] to work on this alone; they need a social worker to work with them on this case because it's quite complex. So maybe having someone to look at a focus why maybe the outreach officers are trying to liaise with housing on certain things can be quite helpful."

Local authorities were beginning to use their definitions of self-neglect as a basis for single or multi-agency case audits, to explore whether cases of self-neglect were being identified or missed, how they were coming to light, and the outcomes of situations where hoarding or squalor were prominent. The use of audit, however, as a tool for learning from cases of self-neglect, appeared to be in its infancy. Some LSABs organised conferences and had profiled self-neglect in that way. One manager thought that a conference on self-neglect had given the authority the energy to keep proceeding with policy and practice development because:

“It’s caused so much interest among staff. It’s clearly a major issue among staff, it’s come up on several people’s cases and obviously we have the serious case reviews. So it’s definitely a buzz word around. We haven’t really provided people with any solutions yet at this stage, but people are interested, it has been part of the conferences.”

The point here is that self-neglect is being mainstreamed, using safeguarding networks to help a message travel, and linking into the current levels of practitioner interest. Thus, in one authority, monthly lunchtime meetings had been established, a practitioners’ alliance for safeguarding adults, to which cases could be taken for discussion. One meeting had focused specifically on self-neglect and had included cases that had been in the media. Even, as in this local authority area, where a formal programme of self-neglect training had yet to be rolled out, there was an appetite for discussion groups that began with the question, ‘What do you think people would do?’ As the manager observed:

“People are fascinated in this and obviously anxious about it and it needs more support probably. So there’s definitely an appetite for it. I think once the training comes out people will be really keen because it’s obviously on their agenda.”

In another local authority a safeguarding manager periodically collated SCRs and was running a group where the findings were disseminated, with a focus on why problems had arisen in such cases and whether there were policy gaps and practice shortcomings locally that could result in a similar type of scenario. These groups were being held quarterly, routinely attracted over 50 people, and had also begun to reflect on, and learn from, local cases. Feedback was then being used to inform protocol development, for example, around risk assessment, and to bring self-neglect to the forefront of people’s thinking. Whether or not groups and forums had been set up specifically to focus on self-neglect or safeguarding more generally, or other specific issues such as pressure ulcers, they were experienced as promoting and embedding integrated working across health and adult social care as well as providing openings through which to reflect on cases and lessons learned.

Access to specialists

Managers felt that specialist advice could be extremely useful in dealing with the complexities of working with adults who self-neglect, but also identified resource and cost implications to its provision.

Examples were given of where frontline teams were being supported in the handling of complex cases by specialists in safeguarding, mental capacity assessments, DoLS, and mental health assessments. This support might include undertaking joint visits, attending case conferences or strategy meetings, providing advice and running groups in which cases could be discussed. Specialists were also used to support protocol development and to deliver training. In one local authority, managers had ensured that there was a safeguarding specialist in every locality mental health, learning disability and drug and alcohol team, whose role was to support practitioners with complex cases, including self-neglect.

The smaller size of some local authorities did raise some anxieties about the lower volume of practice exposure to self-neglect and the availability of specialist expertise, both legal and safeguarding, in terms of mental health, mental capacity and DoLS:

“We’re a very small local authority and with it does not go the same degree of expertise within our legal department and within our management structures, as say the bigger authorities where you’ve got neglect coming in virtually every day, given the population.”

“... there’s a poverty in terms of our legal department trying to replicate the bigger authorities, we don’t have that level of skill.”

Access by practitioners to legal advice was a need acknowledged by managers, to which they had sometimes responded by organising workshops with solicitors. Earlier research (Braye *et al*, 2011a, 2013) has identified that practitioners often lack confidence in their understanding of the range of possible legal interventions. Those findings were echoed in this study, with the corresponding challenge of identifying levels of legal literacy and positive ways of promoting it, for example, through unrestricted access to local authority legal services, alongside training and guidance. As one manager responded:

“Workers who come across these cases on a daily basis need access to appropriate advice and guidance support. I think this is what these procedures try to do. It’s about permission to seek legal advice. I wouldn’t expect my social workers to have complete knowledge of every legal duty that they have. It’s about highlighting when you should seek support, seek that advice, I think that’s the important thing... We have three social care lawyers within the council, who are very knowledgeable.”

Access to lawyers was reported to be “very useful” because “it’s acknowledging the fact that we are not legal people.” Legal advice was a way of ensuring that “we keep ourselves safe in terms of making certain that we are covering the bases when we are offering services”, including giving information about who people can contact if they wish to engage, and “checking back with individuals and never actually shutting the door.” Not all local authorities, however, allowed such unrestricted access to legal advice, with an internal market operating, with attendant cost implications. The result was that adult social care managers were expected to screen the level of need before social workers could ring the solicitor for advice and guidance.

4.1.5 Data collection – estimating the volume of self-neglect work

As is commonly the case nationally (see Chapter 3), none of the local authorities visited as part of the research collected data on self-neglect either through adult safeguarding or adult social care, despite recognition that such data would be useful to track case outcomes and to protect the balance of the workforce by ensuring the availability of knowledge and skills for working with self-neglecting adults. This was also despite recognition that adult social care teams and primary healthcare staff were working with cases of self-neglect on a daily basis, and that local authorities and their partner agencies were spending “much time, energy and effort” on these situations. The usual reason given for not collecting such data was that the DH did not require the information. Managers, however, also commented on antiquated

information technology (IT) systems, the absence of categories on databases and assessment forms to capture self-neglect, the uncertainty about where self-neglect work – and management oversight or responsibility for it – sat, and the difficulty of consistent definition.

“In terms of self-neglect, no, we’re very much restricted in terms of our data collection, although we do a good job compared to some of the local authorities, because we’ve got a very antiquated care management system and it doesn’t gather adult safeguarding data. So we’ve set up a separate database.... So at the moment, it’s very home-grown but it very much goes through the definitions of physical abuse, financial abuse, discrimination ... it’s only when you drill down in the audits that you actually look at it and say, ‘oh yeah, this is self-neglect.’”

Neither strategic nor operational managers knew precisely the volume of self-neglect work being carried by teams. Some estimates were impressionistic, based on supervision and team conversations. Some managers had undertaken audits and were able to provide a percentage of cases where self-neglect featured from the overall sample inspected: “I think of the 27 cases that I audited, four of them alluded to self-neglect.”

Gathering data on self-neglect work is complex when cases come through a variety of teams and agencies:

“The other issue is because the local authority isn’t the only lead agency [for self-neglect work] so presumably somebody could be using those procedures from health and we would know nothing about it, so it would be patchy data anyway even if we did collect it here.”

“I think we’ll struggle if I’m honest, because it’s not something we routinely collect.... I do think the teams could pull that information together fairly quickly because within the teams, this is a high-risk group of people. They’re always going to be allocated to a worker because they’re people who folks worry about.... So it wouldn’t be too difficult to pull it together, but I think you’d have to be clear about what you were asking for in terms of that definition.”

This last quote highlights the challenge of having an agreed definition of self-neglect that would guide staff when entering data onto a record system. One local authority was beginning to use its VARM system to record add-on information regarding self-neglect. Another local authority, using the same system, was relying on individual staff to send in notification of self-neglect cases for entry on their social care record system. Another manager could envisage including within databases specific questions about self-neglect, providing the technology was capable of managing this, the local authority adopted an agreed definition of self-neglect, and both safeguarding and adult social care teams participated:

“We collect data around many issues and it could be possible in the future. I think what we probably haven’t established is what it is that we need. Our systems aren’t brilliant. At the moment we can collect data on safeguarding because all our safeguarding documents go onto our database and therefore you could add in a

question. For example, we've added in a question about 'Is this safeguarding concern related to domestic abuse? Yes or no?' It's as simple as that, and then of course you can run a report to see the potential safeguarding concerns that are linked to abuse."

The local authority concerned in the above quote was intending to develop "some home-grown systems" to capture self-neglect data, demonstrating again that systems could be devised or adapted to capture volume and outcomes of activity.

4.1.6 Triggers for management and strategic action

Particular triggers could be identified that had led to review and development of practice. These included: SCRs; complex cases; involvement by the courts, Ombudsman, Care Quality Commission and partner agencies; the absence of data; staff anxiety; concerns over the workforce skill and knowledge base; and attitudes.

Serious case reviews

Five of the seven local authority areas visited as part of the research had commissioned and completed reviews, or were considering what type of review to hold, in relation to serious self-neglect cases. Significantly, in terms of self-neglect residing outside the legal framework for adult safeguarding at the time of the research, in each instance more SCRs had been commissioned in relation to self-neglect cases than other types of adult protection incidents.

"It's very significant, because we've had more case reviews in [name of authority] of individuals who've died of self-neglect than we have of safeguarding. Which I think is quite telling."

Without exception, the completion of an SCR or management review had acted as a trigger for the development of guidance, protocols, procedures and/or policy. Investigation of the circumstances of such cases had prompted a realisation that self-neglect was a challenging area that "needed a protocol, a framework for working on it." Thus:

"I think in terms of the board, because we've had a number of serious case reviews, members are very aware of it."

SCRs had identified how challenging this area of work is, and pinpointed how cases had not been handled well. This had prompted development of policies for self-neglect and, additionally in some instances, procedures for specific manifestations of self-neglect, such as hoarding or mental capacity assessments.

"[Name of service user in SCR] was a case in point, of people saying, 'she has capacity.' For what? To make what decision? 'She has capacity to decide to live like that' – well frankly, who decides to live like that? So people have moved on from that, I think."

Some respondents identified that their LSAB had turned to other boards that had already developed policies and guidance as a result of serious incidents. Indeed, some managers felt that it had been difficult to make progress in developing a framework for working with self-neglect, or for adult safeguarding more generally, without a serious incident to trigger reflection.

“I think we have more success when we have an issue. Currently we’re undertaking – it’s not around self-neglect – but we have got a serious case review ongoing at the moment and I think that’s really focused people’s minds at a very senior level in those organisations.”

The experience of having to account for something that had happened certainly appeared to concentrate people’s attention on cases of adults who self-neglect, and to highlight where an LSAB and its partner agencies did not have anything in place to guide practitioners and managers in such complex cases. Thus, an SCR in one of the local authority areas visited as part of this research, coupled with SCRs in a neighbouring authority, was:

“... part of the push and it was certainly part of it being heard at the board. Because obviously that action plan for serious case reviews has to go to the LSAB, and therefore it ... it certainly was a driver to say we’ve got to get this resolved and it certainly was a push when things were getting delayed. We were getting quite a lot of pressure to be, like, it’s got to get done, it’s got to get done.”

However, the process of commissioning and completing an SCR was not necessarily unproblematic, as a review of 40 commissioned and/or completed inquiries into self-neglect cases has identified (Braye *et al*, in press a, b). One manager compared an SCR process in a neighbouring area to one that had been completed by their LSAB:

“It was a local authority one only, it wasn’t multi-agency. I think the reason given was that they were so pushed because of having to get it done, that was as good as they were going to be able to achieve. But to me it felt like, if it’s just local authority, it doesn’t really work for self-neglect to me, it’s not one of those issues that you can say as a single organisation you can do in isolation.”

Nonetheless, where SCRs had been commissioned or were being contemplated, they were seen not just as triggers for the development of protocols and guidance, but also as mechanisms for learning and service improvement. One manager referred to an unpublished SCR not in the public domain in order to protect the surviving members of the family of the adult, who had died from complications arising out of self-neglect. Recommendations had focused in part on robust systems for information sharing between agencies, and the importance of escalating to senior managers concerns and risks that appear not to be capable of mitigation. This SCR had also highlighted that not all adults who self-neglect live alone, and that those attempting to complete assessments of risks and needs should strive to understand relationship dynamics in the household and, where appropriate, the impact of learning disability on how an individual understands their situation.

Thus, SCRs and management reviews can assist in building up an evidence base of what good practice might look like with adults who self-neglect. Such evidence includes looking for the indicators of self-neglect, having the confidence to challenge someone who appears not to wish to engage, and having a broad perspective rather than a silo approach to one’s professional role, including escalating concerns. One manager articulated the learning from those reviews:

“I think one of the big learning is about professionals going into situations like this, about not just thinking of the task that they’ve gone in to do, but to look at the wider circumstances. So you’re not just going to give somebody their depot injection, you’re looking around what else is going on in that household. Looking at the triggers, sharing that with other people, I think is the key lesson for us. Again about workers being in a position to say it to their manager, their supervisor and worry about the situation, even though the person says they’re alright, they don’t want to engage, what can we do about it?”

This emphasis on developing an evidence base of what good looks like when intervening in cases of adults who self-neglect, rather than just focusing on creating additional policies, emerges from an account from one manager. Here the LSAB was considering whether to commission an SCR in response to the outcomes of a case in which there had been a death through combined self-neglect, neglect and service refusal, and where practice on raising alerts, inter-agency communication and monitoring had been poor. The manager’s focus is on what may be learned from such reviews.

“Even if it doesn’t go to serious case review, we’ll bring in someone independent because I think more and more we’re in fear of missing something because I don’t think there’s a common understanding, common agreement about how you tackle these. With all the drives for efficiency and everything, it will be ‘we’ll close that one because it’s [another agency] now’. So a sad case but one that I’m determined that we’ve got to learn from.”

Complex cases

Triggers for management action could also come from awareness of complex cases, other than those that had reached the threshold for commissioning an SCR.

“We’ve had, over probably the last maybe six or eight years, a number of quite high-profile and high-risk cases, probably about four or five, where the amount of resource that’s had to go into try to manage those cases at every level has been massive.”

These cases provided a focus and driver to give managers as well as practitioners robust guidance. The imperative also appeared to facilitate creative and effective practice. Cases could be complex because of disengagement by the person who uses services or on account of the demands they made of service providers. The search was to give all staff a framework to deal with those situations rather than struggling on and not achieving any change. In that sense, the driver was about creating a sense of safety for staff:

“I think it is about liberating staff to try different things with people. So this isn’t a covering your back exercise, it’s about getting workers to look at different interventions, different means of engagement with people. Ultimately they may not have the desired effect, but I think if we can evidence that we are trying to do that, I think that’s what good social work practice should be about.”

Vignette: Elsie

Here the practitioner focused on building a relationship on the terms offered, finding ways to build greater safety through practical mechanisms, then using the motivation of a crisis to create change; finding the right carers to work with respectful encouragement was crucial to the success of the intervention.

Elsie, in her eighties, had been collecting books all her life, and treasured her valuable hoard, which now filled every inch of her property, with boxes piled to ceiling height. With diabetes, relatively immobile and in very poor health, she was unable to leave her home, and was reliant on neighbours to drop off shopping.

She was fiercely independent and mistrustful of visitors since some thefts from her property some years ago. She admitted the social worker to her home only with great reluctance, and sometimes not at all, although she would allow him to remain on the doorstep to talk through the closed door. She consistently refused to have anything to do with cleaning her home or clearing any of her belongings. The social worker felt it was a case of one step forward, two steps back; Elsie agreed, for example, to the fitting of fire alarms but managed to remove them herself immediately afterwards. He therefore focused on securing practical benefits on her terms, such as improved income support.

A health crisis occurred in which she lay for some time unaided until neighbours alerted the police; this enabled the social worker to raise again the prospect of providing help, relying on the trust he had built with her. Elsie agreed to let some of the books go and to allow other boxes to be re-stacked more safely. A small ongoing care package was agreed, with carer visits from a specialist agency skilled in building rapport to prompt her in self-care. She agreed to the installation of a key safe so that they and medical staff could enter if she was unable to open the door. The social worker felt that while the solution was not ideal, and risks remained, potential harm had been contained and Elsie's lifestyle respected.

Courts, Ombudsman, Care Quality Commission and partner agencies

Sometimes criticism from a Coroner or Local Government Ombudsman could prompt action, for example, the development of tools for assessing mental capacity or risk. An inspection by the Care Quality Commission had acted as a trigger in one local authority for proactive work to address the concerns arising from self-neglect cases. Elsewhere the spur to action had come from concerns expressed by partner agencies, such as fire and rescue about hazards in the home, housing providers about cases referred for tenancy sustainment and support, or the police about inappropriate call-outs. The request had come for engagement by all partner agencies in devising an effective, robust response, which had prompted some LSABs to develop VARM systems.

In one example, the trigger for action seems to have been the awareness of fire risk problems, highlighted by two very proactive leads, one in fire and rescue and one in adult social care. They used research on self-neglect and fire hazards to develop a way forward, including referral routes. Another example, where housing had triggered a concern and adult social care safeguarding specialist staff had worked alongside to develop and then pilot a response, recognises the pivotal role of housing in identifying and supporting people who self-neglect, and of adult social care in devising strategies, referral routes and plans.

“What happened is our Housing Tenancy Sustainment Team were really struggling, because what they found is if people were self-neglecting and therefore the property was being neglected often as well, they were left, as they put it, holding the baby.... The person had refused all other support and wasn’t eligible for any other support, and so everyone else they felt walked away ... and because the person was living in their property, they couldn’t walk away. We agreed to set up a pilot, where they could escalate cases [and] they had a process for how they would within their team to realise that something might be getting to the stage where it needed referring.”

The pilot involved a direct link for housing staff to a senior operational adult social care manager who would convene a multi-agency meeting to discuss the case and find a solution if all relevant teams, such as mental health, had undertaken work and risks remained. As the manager observed:

“There also seemed to be a really different view on the level of risk. What the Tenancy Sustainment Team were telling me was an extremely high risk, then when I looked at all the notes from the care coordinator ... they were feeling that the risk wasn’t that high at all. So I said, ‘You’ve got to establish a joint decision as to which one you think it is’ ... now he’s going temporarily into a placement while they can do a bit more work with him to decide what support he needs.”

Absence of data – a sense of not knowing

Another element behind the increasing focus of managers on self-neglect had been the realisation that the full extent of the problem was unknown because of the absence of data. The following comment captures this quite graphically:

“So while we’re aware of most of them, and we can provide that data either to the Safeguarding Board or to the Director of Social Services, I just wonder whether or not what we ought to have is more of a sense of the risk that the authority faces; the risk not only of self-neglect, but the very high risk safeguarding cases that are going on, the high risk deprivation of liberty cases where we’re really teetering on the edge of human rights. That would be something that would be useful for the Partnership Board, or that information to be fed to senior managers within organisations ... that isn’t around and this is what’s missing.”

Some managers had conducted or received data from audits and surveys, for example, regarding the implementation of the Mental Capacity Act 2005, which had revealed patchy or inconsistent practice, and similarly reinforced the imperative of taking action to develop policies, procedures and training programmes.

Staff anxiety

SCRs, whether completed by the local authorities included in this research, or known to them regionally or nationally, heightened awareness and anxiety about self-neglect cases. Some managers recognised that staff could find these cases

frustrating and could feel helpless. This, too, acted as a trigger to develop policies and procedures, and mechanisms such as training, conferences, risk panels and support groups in order to challenge assumptions about working with cases of self-neglect and to develop best practice. Thus:

“Staff, for many years, have just not known what to do with it and they’ve thought ‘it’s not my job, it’s not a duty of care, if this person doesn’t want to engage then that’s my duty of care fulfilled.’ But I challenge that and I think that’s the bit that now staff are feeling perhaps a wee bit more challenged and vulnerable in light of the case we had very locally, and we had a case a couple of years before that as well, and I think the word is out there that, perhaps at Coroner’s, sometimes our practice is questioned.”

A strategic driver was recognition that staff found this work intensely challenging, and that the organisation needed both to support staff and to cover itself. This involved finding a location or home where self-neglect policy and practice could be developed, either within or outside adult safeguarding, as this manager articulated:

“I think we had a clear view that self-neglect should fit in, in some way, with the safeguarding processes. Although you’re not investing in safeguarding, it seems to be some of the basic principles we’ve adopted in relation to safeguarding relate very well to self-neglect, in terms of the process of investigation and case conferences. I’ve seen frontline staff flounder a little bit, because they didn’t have the framework to deal with self-neglect as they did with safeguarding.... They need the support of their manager, so this gives you a framework to do that, which I think is very important for staff. Also to bear witness, it sounds awful, it’s about covering your back, but I don’t mean it in that way, a process of recording what you’ve done. To evidence that we do what we can with somebody and we’ve tried those different things.”

Concern about skill and knowledge development

However, procedural development alone was recognised as likely to be insufficient. While not all local authorities and their partner agencies were using SCRs, management reviews and serious incidents as learning tools, in training, workshops and support groups, some managers did comment on the importance of using these cases for service improvement. In one instance, for example, an SCR had been critical of the case-holding practitioner for their lack of professional curiosity. This led the manager to review the knowledge and skill sets of staff being employed by the local authority, and to be concerned about the degree to which qualifying and post-qualifying education was equipping practitioners to see a case holistically, in terms of the whole family and the dynamics that have to be worked with in families and households.

Attitudes as a trigger

Self-neglect cases challenge professional value positions. There are practitioners and managers who privilege respect for autonomy and self-determination; others foreground a duty of care and the promotion of dignity, even where mental capacity is present. These competing ethical imperatives were sometimes the driver behind

the development of guidance and procedures, as this one manager describes, with their strong articulation of a duty of care.

"I think the key challenge is, if you go back a stage further, why are we thinking we need to do something for people who self-neglect? Basically what we are about is trying to improve outcomes for these people who won't engage for whatever reason. Then I think we have a duty to try and achieve those outcomes. I don't think we always achieve that, but I think we have a duty to try, for the individual and for the community.... I think [that duty] comes from my professional practice and experience.... So it's not a duty that's enshrined in law or legislation, but I think it's a basic principle that we adhere to: to continue to try and engage with that person. It would be very easy to say 'that person is not engaging, therefore we'll close the case'. I've seen that, I don't think that's good enough."

4.1.7 Current and future organisational objectives

During the interviews, managers focused on their current objectives for developing services with respect to adults who self-neglect. They also focused forward and identified their aspirations for future work. The first three sub-themes in this section relate to current preoccupations ('clarity of organisation of services', 'getting the right support to people' and 'being able to defend actions and protect the organisation'); the subsequent three sub-themes focus forward and consider what could frustrate and what could assist with the realisation of aspirations for service provision when working with self-neglect.

Clarity of organisation of services

Clarity begins with a definition of self-neglect with which the volume of work can be measured and the standards of practice audited. Some local authorities had developed a definition and included it within their practice guidelines, even if managers could not always accurately quote it or recall from where the definition had originated, and were keenly aware of how complex it can prove to settle on definitions.

"Yes it's in there, I wouldn't be able to quote it to you now as I don't know it enough, but it is in there ... but I know that was one of the issues, that we obviously clearly needed a definition ... [and] underneath that we've given some examples. We've struggled with that in safeguarding as well because you can really tie yourselves in knots with definitions."

A clear definition facilitated an operational response by identifying what self-neglect is, what the level of response should be and, in some local authorities, then providing tools with which to assess capacity and risk, consider legal options and the involvement of other agencies, and to seek to engage the individual. In the definition that follows, used by one local authority as part of their VARM system, the focus is clearly on people who have capacity, and one decision to be made is whether the case can be held in care management or should be escalated into adult safeguarding.

“We are very clear, that the person has to have capacity, there has to be no perpetrator and their actions must [create] a level of risk. And we have a scoring tool to say that. So what we’re saying is basically, if it’s under 10 [it] could probably be case managed. It’s only if it continues to escalate that you need to bring it formally in. We’d consider things like their impact in terms of anti-social behaviour ... because if that anti-social behaviour in terms of having a really insanitary dwelling place, or there’s rats and mice running around, is causing neighbours to start to object ... then that would be escalated back into the score.”

Another working definition follows, this time quite broad, which focuses on inability rather than unwillingness, and where intentional self-neglect refers to those people who have capacity and make that choice. So this definition therefore includes adults with and without capacity.

“What we’re saying is self-neglect is an inability, intentional or unintentional, to maintain a socially and culturally accepted standard of self-care, with a potential for serious consequence to the health and wellbeing of the individual and potentially to their community. That’s quite broad, and I think that’s the right approach.”

Local authorities were also devising arrangements for where self-neglect work would reside, both strategically and operationally. Different solutions were being codified. Some local authorities were locating strategic oversight, multi-agency arrangements and policy development under a safeguarding umbrella, while referrals were managed within care management teams. Other local authorities allocated complex cases to specialist teams while other referrals went to locality teams. The imperative for managers was to ensure that at a strategic level self-neglect was recognised. The focus was to ensure ownership of the challenge of working with such cases. Thus:

“Well that’s the worst one, ‘somebody else’s business’ actually, isn’t it? Obviously we are trying to make it ‘everybody’s business’. So we’ll have to see how that goes, we certainly, even though it’s very well established, still have some problems without the safeguarding alert.... So there’s some good messages coming down. It’s just whether they’re always carried out.”

Some managers were also very clear about the overall orientation of their departments when working with self-neglect. In the majority of local authorities visited, the balance to be struck between the competing perspectives of respect for autonomy and duty of care was left to those working with specific cases. In one local authority, however, the orientation of the organisation was clearly stated, the overriding ethos and service culture being one of a duty of care. Thus:

“Obviously as team managers of social workers, we have a duty of care to protect vulnerable adults, so we have a duty to work through and we have obviously policies and procedures that enable us to do that.”

This orientation extended to partner agencies working alongside adult social care, as all the partners had signed up to the self-neglect protocol, so:

“... if there’s any sort of resistance that they can’t come to [a] meeting, [we] remind them that they have a duty of care, they signed up to this protocol and they have to make sure they do turn up.”

“What I think we should certainly say is that personalisation is the default position, choice and control is absolutely the mantra, if you like, within that, but I think if there’s any doubt then it would be a cautious safeguarding approach rather than a very proactive risk-taking sort of approach ... and that’s why we are trying to build into these protocols, to ensure when we make a decision, it’s that kind of balance, and we can demonstrate that we’ve exhausted everything.”

Getting the right support to people

Such developments as self-neglect panels, hoarding panels and high-risk panels, and the creation of VARM systems, are examples of local authorities and their partner agencies endeavouring to ensure that people who are hard to engage are nonetheless offered assessments and service provision. Several local authorities could refer people to groups for hoarders.

“The biggest risk to us is that these people don’t get the support that they need, so I say the main objective is to ensure that that happens and that it happens in an organised and clear way.”

Seeking to deliver the right support required a good understanding of risk. Several of the local authorities visited had drawn on how mental health and learning disability professionals were working with risk assessments and managing risk. Concerns were expressed that in self-neglect cases care management had not been sufficiently robust, and risks had not been assessed at an early stage and then regularly and routinely reviewed. This required a proactive preventive approach that did not necessarily sit easily with eligibility criteria. One manager was especially clear that, alongside an assessment of need, there had to be a risk assessment in cases of self-neglect. A person’s needs might not yet be substantial or critical, but moderate level risks might sway decision making.

The focus on risk and the demanding nature of self-neglect cases had led one local authority to establish a team of specialist social workers who were used to working with, and had the skills for engaging with, people who challenge services as well as themselves and their communities. A very clear line management structure, accompanied by very clear formulations about handling constant communications from some self-neglecting adults, had been put in place so that adult social care and its statutory partners were responding uniformly. This had given a clear platform that had enabled a few people who use services to engage where they had not previously done so.

Throughout the research, examples were given of internal policy development to ensure that cases were being monitored and the multi-agency network acting in a coordinated, planned and agreed manner when faced with service refusal. Managers emphasised the importance of understanding that “when someone tells you to go away, you do not close the case and effectively abandon the individual.” Moreover,

given that self-neglect can be experienced as an elusive concept by practitioners, and that such cases can be stressful to work with, the exercise of professional judgement and discretion about when to escalate concerns and about how best to seek to engage and maintain a relationship with a service user had to be supported by protocols and a system of case conferences, panels and multi-agency meetings.

“We are looking at those procedures being followed where we’re looking at a significant risk, because obviously there’s going to be levels of self-neglect and there’s going to be situations of people dealing with – probably on a daily basis – someone who’s not keen to take their medication, or they’re not eating as well as they should do or whatever, but it’s going to have to be a judgement call of practitioners to the escalation point of thinking actually the risk is so high.”

Getting the right support to people for some managers meant emphasising the importance of seeing the whole person, rather than just working in silos, and entailed a critique of the ideology of personalisation and its impact on what workers believe that they can do. Thus:

“It’s also because we’ve specialised, so we’re homing into just particular parts. The other thing about personalisation if you think about it, is that we’re not the professionals, it’s the service user who’s the professional, they know the best; why question all those self-assessments and all those kind of things. So that part of our skill base is kind of eroding.”

This led some managers to emphasise the importance of negotiation, respectful curiosity and challenge, and consideration, where appropriate, of more authoritative and decisive practice, including, if necessary, coercive powers to secure engagement. There was, therefore, an aspiration to strengthen practice, rejecting the automatic ‘they’ve got capacity, walk away’ approach. There seem to be two goals here – support for staff and ensuring there are robust interviewing and risk assessment processes through which judgements can be made and a duty of care satisfied, using coercive powers if need be.

“What we’re trying to do is give a framework to those workers, both to support them in that piece of work, but also to recognise that dealing with those cases of people who self-neglect, it’s no good just saying those people have got capacity so they can live like that. We have to make some judgements and we have to be in a position to support the workers, in terms of when they need to escalate those cases for different reasons, to make the whole process robust.”

Vignette: Stan

Here the practitioner is clear and honest about the risks posed, finding a way to provide respectful challenge and to balance hands-on and hands-off approaches.

When Stan, a man in his fifties with serious health problems, spoke about his previous living conditions, it was clear that he had resigned himself to whatever happened to him. The house had been horrendously damp, filthy and infested with rodents, but he had no expectations of any other way of life. After an acute health episode that resulted in hospitalisation, the condition of his house precipitated a crisis. He could not be discharged to his home, due to the likely effects of its condition on his health, and was eventually re-housed.

Stan said that his quality of life had improved drastically following the move. However, he still neglected his self-care, and said that he struggled to motivate himself. Where his self-presentation had improved, “most of it was encouragement, if I didn’t have that encouragement to do things, I don’t think I would have changed.” This encouragement came from his social worker and from the carers who now visit him daily. His social worker commented that he had to ‘push’ Stan to do some of his organisational tasks and self-care: “I can be quite hard and quite outspoken and I did give him nearly a lecture.” Stan himself did not see it quite this way: “He’s down to earth, he doesn’t beat around the bush,” but he also “knows when to back off.” A viable balance between hands-on and hands-off approaches has been achieved, but the worker remains constant, recognises ambivalence, and doesn’t take at face value Stan’s reluctance to engage.

Being able to defend actions and protect the organisation

Defining self-neglect and agreeing a multi-agency procedure for working with adults who self-neglect also had a protective element. Some self-neglect cases are subsequently reported to the Local Government Ombudsman and/or the Coroner. Equally, they may become the focus of an SCR. Thus, LSABs might understandably be seeking reassurance that policies were followed, and that standards of good practice were adhered to. Thus:

“If I’m absolutely honest, there is an objective in there as well to ensure that if something does go wrong, it’s also quite clear and defensible that actions that were taken, were thought through, and there was a plan. So there’s a bit of protecting the organisation as well in there, which is reasonable.”

“So the main objective is ensuring people get the support that they need in a way that is useful to them, and if it really can’t be achieved, that the organisation can feel that it has actually done what it needed to do, and there was a process in place.”

Aspirations

The need for data about self-neglect cases was acknowledged by all managers, but the search for an effective performance management reporting system, which included data on self-neglect, was sometimes seen as a work in progress, as an aspiration.

“Yes, absolutely, we will have to. We have to work out how we might be able to do that. All that data will be important for me internally now, but it would be useful if there was some national framework for something like that.”

Policy development remained aspirational for some of the managers interviewed, including the goal that the guidance would be a practical working document for staff that impacted on practice. Thus, this quote resonated in several local authority areas:

“A common understanding and a common approach and, even if we have to develop good standard practice guidance ourselves before the Department of Health, we really do need to do that. I don’t think we can hold back and my director is very, very clear that this has got to be a priority area regardless of what goes in the Care Bill or not. So in terms of my workload, she’s asking for self-neglect to go further to the top of the agenda.”

Here was the aspiration to build good social work and multi-agency practice through procedures:

“I think what we were trying to get at with the self-neglect procedure, is that it is about that good old-fashioned kind of joint working and working with the client and building relationships.”

“What we tried to do was pull together all of the options, even if you have a multi-agency approach, it can be still a bit of a grapple of ‘We can’t do anything, can you do anything?’ ‘We can’t do anything either, so what can environmental health do? What can nurses do, what can doctors do?’ ... and trying to pull all that together in there so at the meeting or outside the meeting, people can look and say, ‘what are your options?’”

Another priority was to begin the roll-out of recently agreed policies and procedures, and giving thought to how best to do this in order to ensure impact and the embedding of LSAB and local authority expectations in practice. Aspiration to get the guidance launched clearly emerged, but also an interesting recognition that in order to engage people with it, to secure operational staff buy-in, something had to be offered too – a resource – the booklet that is meant to provide a handy guide for frontline staff in agencies that are crucial in spotting self-neglect.

“We’ve got to do this right to get it to staff, because it’s only as good as people actually working to it, and finding it useful to work to. What I’m trying to do is get that booklet finished, because ... if it’s got the accompanying resources with it then people might be more interested in looking at it. Then, after that, how do we then monitor it, know exactly how it’s being used?”

Picking up the theme of audit and monitoring, the following quote captures that aspiration well:

“The difficulty at the moment is although we’ve got [procedures] I wouldn’t be able to say to you this is how well it’s working yet, this is how it’s all rolled out; but that guidance ... is quite ‘how to’, as it just goes through the steps of the sort of things that you have to

consider and then about running a meeting. I'm hoping it's fairly practical for people to follow rather than an overarching policy statement, it's actually meant to help staff to follow."

Some managers chose to highlight the development of additional services as one next step in relation to self-neglect work. For instance, one manager wanted to improve the quality of practice around service refusal. Another manager had been impressed with a floating support service that had been developed by a neighbouring council, to which social workers and other professionals could refer for assistance and for the organisation of blitz cleans. The manager contrasted this with what their own council was currently providing, and was hoping to develop a service that was better coordinated and conducted more in partnership with the person who uses services, with floating support workers who could be present to help with negotiations.

"What I would like is something that's a bit more coordinated, maybe if we had one or two [blitz clean] teams that we could regularly rely on and we also incorporated some of that time-consuming work where people say they want to go through things and you have to give them that opportunity to go through those things, but it probably isn't officers that can do that kind of work."

Continuing the theme of service development, early intervention was another aspiration: "What we want to be doing is trying to engage with people as early as possible ... far earlier than when it reaches a crisis point."

What does or could get in the way?

Managers were also conscious of various challenges to achieving their aspirations for strategic and operational change. One major barrier to strategic change was felt to be the absence of a clear statutory remit to bring agencies together to agree procedures for working with self-neglect. This was contrasted with DoLS and the Mental Capacity Act where managers did feel confident in using legislation to insist that other agencies accept their responsibilities. The Care Act 2014 requires agencies to cooperate with respect to adult safeguarding but, currently, self-neglect lies outside that field of focus.

"It's the fact that there's no clear statutory remit.... It's not really clear therefore where it [self-neglect] sits and who needs to take responsibility. Without even getting on to the challenges of the people that we're working with and clearly they are going to be people that have potentially quite complex and challenging lives."

Alongside the absence of a statutory mandate was criticism of the paucity of central government guidance with respect to self-neglect policy and practice, contrasted with the perceived volume of statutory and practice guidance with respect to adult safeguarding. It added to the difficulty of "getting people to really understand their role, understand the risks, responsibility and actually take responsibility" and securing agreement on local guidance.

"It's trying to make that multi-agency meeting a requirement. What was happening before was you'd ask someone to a meeting and they'd go, 'oh no, they're not on our books,' and you'd go, 'I know they're not on your books, they're not going to be on your books, but we still need you round the table.' It's those sorts of

challenges, I think we've got senior management buy-in now, because obviously it's been signed off by the board, but I think that where we're going to struggle is on an operational level with people going, 'I don't know anything about this, I don't know what is about and they're not on my books and our team is busy.' So there's going to be some of that, and we won't have any kind of law to be able to say, 'I'm afraid you've got to join us this with this.' So that's going to be tricky."

The wider political context was also commented on, namely, the construction of the Care Act with its exclusion of protection orders and a power of entry. Thus:

"Their [central government] understanding of the social care profession is to minimise the intervention of what care managers, social workers should be doing. So when you come to issues of complexity, it doesn't fit within the norm box of personalisation and re-ablement, it's outside the box."

Another concern was the availability of resources for developing and implementing good practice guidance with adults who self-neglect. Sometimes this emerged through a concern with the blanket applications of thresholds and eligibility criteria. Sometimes managers were worried about the sustainability of early intervention and prevention services, established with short-term project funding from the DH, as they would become vulnerable to financial constraints when the specific funding source ended and the projects had to be incorporated into, and funded from, mainstream budgets. Sometimes the concern focused on whether there would be sufficient health and social care staff to invest the necessary time in seeking to engage and then effectively work with adults who self-neglect.

"It has felt a little bit with this work that it's been like tacked on, which has been a bit frustrating because it is so core."

"Social workers are carrying huge caseloads, between 30 and 40 cases for care management; if they are investigators, they most probably have two or three safeguarding alerts on the go as well and if they are also qualified to undertake DoLs assessments, they have probably got one on the go as well."

What would help?

Unsurprisingly, what managers thought would help to take their priorities forward around self-neglect work was national guidance, namely:

"A very clear steer from the Department of Health and even if it does come by way of some good practice guidance, because ... what I find is in talking to elected members and other agencies, if you've got this ... it's good to be able to say to people, 'somebody will be looking at whether we're adhering to this guidance, you might not have a duty to do it but it's good practice', and you can audit yourself against good practice and at the moment, we can't audit ourselves against anything."

Managers referred in this context to *No Secrets* (DH, 2000) as providing a framework that offered a driver to local authorities and their partners. In addition to national guidance, they hoped that this research would also offer guidance that would provide

a framework around which they could “shape their services.” Government guidance and research findings were seen as giving managers “a bit of extra clout” in the sense of being able to articulate the good practice and outcomes that services should strive towards.

Workforce development also emerged as a key priority, so that practitioners and managers have the tools to achieve personalised and outcomes that express a duty of care in the most challenging of circumstances. Training therefore emerged both as an aspiration and as something that would help agencies to achieve policy goals. This might involve using external speakers who could offer an external, potentially different and hopefully reaffirming perspective. However, to ensure that research-informed learning was applied, value was seen in case presentations to peers and colleagues, perhaps supported by contributions from legal and safeguarding specialists, where employers sanctioned time to reflect and research as a means of developing in-house expertise.

“What we then need to do is give people the tools to be able to try and achieve those outcomes. I think we are probably on the early stages of a journey. You mentioned workforce development; I think there's a lot to be done around that, some guidance from central government might be helpful in this area. It gives us some further framework for people to work in. So we're very much in a vacuum at the moment with this.”

Value was also perceived in network forums, using the internet to engage with other professionals in order to explore the challenges presented by cases. Otherwise social work could be isolated and isolating. Networks of professionals, a learning community, used a wider audience.

“You don't have to say who the person is but we've got this issue and if there was a network of other professional people grappling with the same thing, 'we've done this, this is how we've worked' ... the more experience you have, the more little toolboxes you have and if you cast that in an internet forum, with a wider scope, you can then work with some of these ideas.”

One manager talked of their local authority and LSAB approach to developing what were now a number of very knowledgeable practitioners. In addition to monthly half-day courses on procedures for working with vulnerable adults at risk, including those who self-neglect, information was made available on all the social care and health intranets. Safeguarding and self-neglect specialists located in adult social care, mental health and healthcare settings were also available to offer daily case advice, with a three-hour turnaround maximum in terms of going back to them and saying, “right, you've clearly got a VARM case, you've clearly got a self-neglect case, we'll send you the paperwork, we'll send you the briefing information, come back to us when you get it.” This support was seen as essential for practitioners working with cases that they found “incredibly frustrating and time-consuming”.

“They feel very isolated with very high-risk cases; that's the bit we've got about trying to make sure that they are flagging it up to their managers, sharing it with us, so that they're not carrying that risk on their own, because ultimately, these are people who are likely to end up seriously ill or to die. I don't think frontline

practitioners should be carrying that. I think increasingly as we've got teams increasing in size, fewer managers around, my worry is that might become the reality for a lot of practitioners."

If staffing emerged as a concern, something that, if not handled appropriately, could get in the way of providing effective services, then having the right staffing mix was seen as a crucial facilitator of change. This meant having a balanced workforce, with sufficient social workers to take lead roles, access to specialist expertise at crucial points, and knowledgeable and skilled healthcare and social care staff to offer high standards of care.

"I think the importance of having social workers at the front door is that you effectively and properly triage the stuff that comes through, so people can spot that this is going to be one of those cases that may take some time, and effectively pass that to the appropriate people to deal with it. I've felt it was quite critical to have that professional input at that front line."

There were examples of integrated healthcare and adult social care teams, which were reported as greatly facilitating ownership of cases of self-neglect, and co-working with people who use services and family members.

Continuing with the theme of ownership of self-neglect policy and practice, what was seen as helpful was keeping self-neglect "on the agenda, keeping the discussion going" at LSAB level. In other words, what was helpful was strategic leadership in taking things forward, with the LSAB setting the agenda to be taken forward by task and finish groups.

"I think having it in the Safeguarding Board is helpful for endorsement. It's useful if organisations have got that senior management buy-in. I think, unfortunately, where things have gone wrong in other areas is helpful because you can use these examples. I think trialling and testing some of it, a lot of it's going to be down to relationships in a goodwill way saying, 'well, let's trial this out and see, let's all meet.' What will help then is if some of that is successful, people will go, 'actually that wasn't just an extra piece of work. Going to that meeting that actually moved things on and was successful.'"

In addition to staffing, time was also a precious commodity to change people's mind-sets, to enlist buy-in to self-neglect work, and then to focus professional activity effectively. This required strategic leadership.

"And a bit more time, because with safeguarding when I first came to this role, it was still people saying, 'what's all this about? It's nothing to do with me,' and yet now no one questions it anymore and it feels quite straightforward. So it's getting people to be part of it and understand it. It will get there but it's just like anything, when it's new and obviously with the pressure on resources, the message you've got to get across is that this isn't an extra thing, this is the core work that if we get it right could save resources in the long run. The key thing that came out of our serious case review wasn't that actually there's this gentleman that no one had been doing anything with, and actually we should have done

something; there was a gentleman [with whom] everyone was doing loads of stuff, it's just that none of it was successful. So all of that was costing money if you look at it purely from resources ... and I suppose it's trying to get people to understand that this doesn't mean extra resources; this in the long run could save us."

However, that was not the end of the story or challenge. Having developed policies, procedures and protocols, the next step was to embed them in practice, which required a focus on monitoring and both intra-agency and multi-agency audit. That may well require extension to self-neglect cases, which often sit outside safeguarding work that is the subject of auditing by LSABs.

"Yes, the key is really going to be ensuring people are actually using it, and that somehow we are monitoring the quality of it."

Given the complexities of developing and then tracking implementation of new procedures, having available models from other local authorities and LSABs was appreciated. Managers were keen to learn from other councils and their partners, but not all websites were found to be informative and useful, and not all regions seemed to promote practitioner or safeguarding lead discussion forums. One safeguarding lead reflected:

"I haven't really had an in-depth practitioners discussion with other heads of safeguarding, or other types of roles about how are you managing this issue.... I think that would be really useful, because otherwise we could just end up feeling that we're clueless to what we are doing with it. I haven't always felt completely clear with this work in a way I have with other pieces of work."

One of the things to emerge from previous studies of working with self-neglect (Braye *et al*, 2011a, 2013) is that sometimes practitioners experience the workflow through adult social care – those now fairly well proceduralised, codified and time-tagged workflows or pathways – as not fitting with cases in which self-neglect is apparent. In self-neglect work, practitioners might spend three months on the doorstep and another month talking through the letterbox before the door is opened, without making obvious progress. Sometimes for the providers there isn't an obvious independence outcome, just longer-term engagement. Indeed, in this research project, managers acknowledged the length of time and the slow pace of change that characterised cases of self-neglect. This could present a strategic challenge.

"I think it's a huge challenge because adult social work and adult social care is very much now 'get in, assess, provide a service and deliver it and close it,' whereas this is the opposite often, isn't it? There's a delay in how you complete your assessment. It is the onus on you in terms of performance indicators, it is about completing your assessment in certain target timescales, delivering the service, dealing with the volume. I think we are lucky in [this local authority], we have got quite a number of experienced social work practitioners. We haven't gone down the route of replacing social workers with care management. I don't mean that disparagingly about care managers at all. So you have people who've got that basic social work practice and principles there. As a strategic manager, I have to keep that balance of saying, 'yes, I

need that volume completed and the turnover,’ but also recognise the fact that if we have some severe issues around self-neglect or safeguarding, that takes time. It takes perseverance from staff and they will get my support at least.”

Managers acknowledged the need for flexibility in service structures. A broad view needed to be taken of how care management teams organised the flow of work, how departments configured and used targets for performance measurement, and then how practitioners configured their professional role so that they were not just confined by their own service’s focus but were sensitive to self-neglect indicators, and had the confidence to challenge someone who at face value doesn’t want to engage.

Moving forward

What shines through in how managers envisioned their current and future priorities with respect to self-neglect was that this is very much work in progress, the beginning rather than the conclusion of a job of work. Strategic development work could be quite isolating and uncertain, particularly in the absence of models of good practice and an evidence base of what is helpful strategically and operationally. Moreover, self-neglect seemed to present greater challenges than adult safeguarding generally, perhaps because of the ethical and practical dilemmas that such cases present to managers and practitioners.

“You can do all the definitions and all the broader stuff, the tricky thing is what actual process are we saying if someone’s got a concern? Who are we telling them to go to? None of that is clear at all, so those practicalities have been difficult. Are we going to give them a form? We don’t want any extra forms but then how are they going to do it? What is it they’re saying and what is the person receiving the information then going to do with all those things? It hasn’t been very easy at all really, and for some reason, in safeguarding, they just sound much more straightforward.”

4.2 Operational responses: experiences and outcomes of putting strategy into practice

Managers also focused on operational issues during the interviews, the themes for which follow, covering ‘care management’, ‘multi-professional working’, ‘panels and case conferences’, ‘compliance with guidance’, ‘effective engagement with adults who self-neglect’, ‘staffing’, ‘capacity’, ‘levels of legal literacy’ and ‘effective interventions’.

4.2.1 Care management

There was an acknowledgement that a perfect organisational structure might not exist, and that social workers and other professionals should be able to work with people who use services in a personalised and, where necessary, protective way, regardless of structure; thus a ‘one size fits all’ organisational approach to social care work was seen as inappropriate. Self-neglect cases were seen as not fitting neatly into care management, re-ablement or personalised budget approaches to workflow. Indeed, one manager in particular was concerned that adult social care services, and staff within them, had lost:

“... that whole ability to work in a longer-term way with people; it has been marginalised in some ways and yet they are the cases that cause anxiety, take a lot of time, challenge us all, so my worry would be, because of the structures, have you got the people with the right skills and experience ... I am not sure that we necessarily have.”

Flexibility, then, was crucial for self-neglect cases within organisational approaches to work distribution, including timeframes for assessment and decision making about packages of care, and procedures for closure or transfer of cases between teams. Thus, one manager commented in respect of one self-neglect case that had had a positive outcome, as follows:

“Fortunately [the social worker] had a manager in that instance who accepted that he would have a reduced caseload to be able to put intensive support To do it well and to do all the research that he did, you have to accept that you cannot have a significant caseload.”

Operationally, another flexibility that was valued in some settings related to the allocation of self-neglect to either adult social care or adult safeguarding. This depended on the complexity of the case and the nature of the self-neglect being presented. Similarly, allocation to locality or to specialist teams would, in some areas, depend on complexity, such as the presence of severe dementia or mental distress. One particular complexity arose in situations where self-neglect appeared to be accompanied by neglect from a partner or carer. This required skilled work to understand the dynamics between the adults involved and to avoid becoming manipulated by one or other party in ways that could distort the worker's focus and attention.

One manager captured the limitations of care management approaches in terms of offering support in a way that is acceptable to someone who is self-neglecting. They anticipate various themes to follow, relating to effective engagement and interventions with people who self-neglect, namely: co-ordinating who might be the best person to “put their head around the door”; coordinating professionals such as the police, mental health and the GP to ensure that involvement; and recognising the need for a “slow approach” once major risks have been minimised.

“Yet in terms of our care management role, it's about ‘assess, support, plan, personal budget, monitor, review’. It doesn't fit with that either. I think we are aware we don't just close cases; we do our very best, where we know there are specific issues, to do that pop round. So staff ... have people on their case load who haven't got any service provision, but we just keep them open. So the challenge is about that engagement with the person, who's the person to engage, and service coordination I think too.”

Two other managers also talked about the challenges presented by these cases to care management, namely:

“The caseload management process of assessing their needs, provisioning the appropriate services and getting them to the point

where you can place them on review does not sit well with the need to try and engage with people who are self-neglecting.”

“There’s a big challenge around the return to social work values and the need to process service users through the care management route.”

One manager linked this challenge back to personalising, commenting that management “need to rethink personalisation because we are still fitting people to services and not developing services for clients”.

What emerges is a contrast between those managers who “manage work to the letter” of eligibility criteria and performance targets, moving workers on if someone will not engage, and those managers who encourage staff members to persist. One interviewee described this as “a bit of a postcode lottery”. Another said that it depended “on the individual manager’s view as to how far you go with that case.” This could result in workers struggling when advocating to keep a case open.

Vignette: Robert and Richard

Here a practitioner gains managerial support to continue to build a relationship of trust over time, despite an absence of tangible movement in the situation, enabling them to tune in to the individual’s own-paced motivation for change.

Robert and Richard, two brothers with mild learning disabilities, lived in their family home, where they had remained following the death of their parents some time previously. Large amounts of rubbish had accumulated both in the garden and inside the house, with cleanliness and self-care also an issue. Fraudsters had targeted them, resulting in criminal investigation and conviction of those responsible, but they had refused subsequent services from adult social care and their case had been closed.

However, they had had a good relationship with their social worker, and as concerns about their health and wellbeing continued, it was decided that an exception would be made to usual expectations on intervention and case closure. Reopening the case, the social worker had management support to remain in contact, calling in every couple of weeks to see how they were, and offering any help needed, on their terms. After almost a year, through the gradual building of trust and understanding, the brothers asked to be considered for supported housing; with the social worker’s help, they improved the state of their house enough to sell it, and moved to a living environment in which practical support could be provided.

4.2.2 Multi-professional working

Emphasis was laid on communication between professionals, drawing on other people’s expertise to develop an understanding of a situation. That communication, within and across agencies, could be complicated by different understandings of what leads people to self-neglect, and pre-judgements about misuse of alcohol and drugs, repeat callers to emergency services, and about acceptable home standards. This could affect the willingness of agencies to retain involvement when, as is apparent, such cases require long-term working.

“Dependency on alcohol raises quite an issue because again it depends on the individual manager’s view as to how far you go with that case, when someone is inflicting it upon themselves and whether they’re willing to engage or not. There can be quite a judgemental attitude [and] from external agencies like the police as well, or from health and I think sometimes our workers struggle to maintain that case, keeping it open and going.”

Communication challenges could also arise between agencies where one agency, for example, environmental health, would state that a case did not meet their threshold criteria and where there was an expectation from agencies, communities and neighbours that adult social care would “fix the problem”. For example, one manager reflected on working with housing colleagues as follows:

“We’ve worked with them in a number of cases where there’s been hoarding or there’s been significant issues with properties and they’ve supported. The difficulty is where it’s the person’s own home or I can think of one particular couple where it was a Housing Association property and they were really struggling. Environmental health had been, and had done what they needed to do, but it was then left to us to keep working with or try to engage with the couple, with constant phone calls from the Housing Association saying, ‘help.’”

Another manager followed the same theme, talking about alerts from the police, district nurses and community psychiatric nurses where those being referred might be unaware of the exchange of information.

“Well, it’s over to you’ sort of thing. It feels like very often, other agencies can walk away and say, ‘we’ve told social services, we’ve told the local authority, so if something happens to this person, then the whole ‘Daily Mail or the News of the World are knocking on the door,’ then it won’t be us.’ So it’s about that sharing the risk, that’s what it feels like sometimes.”

Unsurprisingly, relationships between professionals at the front line were reported as variable. Sometimes the involvement of a GP or the police, for example, in multi-agency meetings, was felt to depend on how anxious or under pressure they felt in relation to a particular case. A number of factors, however, did appear to facilitate joint working, namely, co-location, adult social care staff being prepared to chase up reports and to time meetings to facilitate the involvement of other agencies, and a history of good multi-agency cooperation that had been supported by particular personalities. An integrated health and social care system was felt to remove barriers to organisational interaction and to facilitate joint working, for example, through attending each other’s team meetings and a joint triage of referrals to enable agreed decisions on responses to referrals. It was generally acknowledged that relationship building takes time, especially when new organisations are created, as in the NHS subsequent to the Health and Social Care Act 2012.

Some specific reflections on contributions to multi-professional working emerged.

General practitioners

Some GPs were reported as helpful in attending or providing reports for panels and conferences; others did not engage, even when efforts had been made to arrange

meetings at their convenience or in their own office settings, and to acknowledge their busy schedules. At times managers had reminded GPs of the protocols and procedures agreed by the LSAB in an effort to secure their cooperation, again, with mixed results. This was also being used formally as a defensive measure, so the records would indicate what efforts had been made to secure their involvement in decision making, just in case the situation deteriorated to the point where a formal inquiry or review might be commissioned. Briefings for GPs on adult safeguarding had been offered, and the creation of clinical commissioning groups was reported as having facilitated such organisational arrangements.

In those local authorities where integration between health and social care was further advanced, social workers and/or community care practitioners had been linked with GP surgeries and were attending meetings there in order to share cases of concern and to discuss adults at risk. This, for example, in one area had facilitated links with community matrons.

District nurses

District nurses were sometimes portrayed as being “very stretched”, with consequently erratic engagement with adult social care. At other times relationships were said to be positive.

Mental health services

Where mental health or learning disability social work and social care staff had been transferred into NHS trusts on Section 75 agreements, some tensions were reported over thresholds, with acknowledged risks that “people could fall between everyone’s eligibility” and the whole person could be overlooked. Thus:

“I think there is some tension there, I won’t lie, because I think their view is we pass over all the waifs and strays their way and our view is they pass them all our way! So there are the people who fall between everybody’s eligibility but actually if you look at the totality of their needs, they do meet the threshold so they are mild but mildly mentally ill, perhaps with a bit of personality disorder, they may have a mild learning difficulty, they’ve got some substance misuse but not wanting to do anything about it; to do everyone’s individual criteria is a bit of a challenge but if you look at them in their totality, they’re very vulnerable.”

Again, where integration between health and social care systems was further advanced, for example, in relation to services for adults with dementia, weekly multi-disciplinary team meetings were being held, involving psychiatrists and psychologists, at which social workers could discuss cases of self-neglect and where responsibility for agreeing ways forward was shared.

Mental health and mental capacity advocates

Some managers reported using advocates “a lot” with good, strong relationships. At other times, relationships could become awkward.

“On occasions it’s very difficult, people will come and tell us what our customers want but they’re not looking at what the risk is and so, say, it’s about looking at alternative accommodation, because the person really is not safe to be at home, but they’ll just keep

saying, 'but that is their wish to go home'. But we can't manage that risk safely and sometimes we find that a bit difficult because it's easy to say what the customer wants, it's harder to actually act responsibly and make the decision that that can't happen and as I say, we never make it lightly but we do have to weigh up the risk and sometimes it's too great."

Fire brigade

Examples were given of close cooperation and good working relationships. Interviewees referred to joint working on devising referral and assessment pathways and forms, attendance at panels, meetings and conferences, and responsive visiting when alerts were received concerning fire risks.

Police

Sometimes the police were presented as engaging only where a crime had been committed, but in other areas police officers were fully engaged with adult social care and with safeguarding, sending in alerts and maintaining a public protection involvement where this was felt to be helpful. One manager noted that police officers were active in targeting discriminatory abuse in communities where particular houses might appear unkempt. One manager's assessment, anticipating a theme that follows about drawing on the professional most likely to get across a particular threshold to engage a self-neglecting adult, was that:

"Police tend to get involved.... I suppose the softer arm of the police, so the community safety type officers and their local authority counterparts, are very good, I have to say. They're very good at being the eyes and the ears, because the community neighbourhood officers again are quite often one of those unlocking tools, because they're not seen as a threat, because they're not going to take their house off them. We've done a lot of work with our community safety colleagues to roll out training specifically for them around self-neglect."

Occupational therapists

Where joint working with occupational therapists was mentioned, this was sometimes described as effective, especially regarding the assessment of executive capacity, namely, the ability to act on a decision and to manage any consequences of it. No particular tensions or role conflicts emerged in this regard.

Housing

Some managers reported having developed good or excellent relationships with housing staff, who could sometimes feel that they were carrying much of the responsibility for adults who self-neglect, especially when they were living in social housing. Occasionally, the high eligibility thresholds for receiving adult social care assessment and services could aggravate this perception. Thus, one operational adult social care manager held monthly meetings with her local authority housing colleagues, to discuss cases of concern, and also had routine engagement with housing association managers to discuss the use of sheltered accommodation and extra-sheltered provision rather than residential care as a way of meeting people's needs.

Environmental health

Relationships were sometimes, although not always, characterised as strong. Examples were given of joint assessments with adult social care staff, discussion of legal options, and cooperation with arrangements to de-clutter and/or deep clean a property.

4.2.3 Panels and case conferences

Managers believed that social workers and other professionals found it helpful to bring self-neglect cases they were experiencing as challenging to multi-professional panel meetings or case conferences. One manager in particular was clear that this investment of time and personnel ultimately led to better value and a better use of people's involvement than "just working on their own agenda and getting nowhere". Alongside available guidance and documentation about manifestations of self-neglect, mental capacity and safeguarding, panels, multi-professional meetings and conferences were opportunities to raise the profile of self-neglect, seek support, share the risks and agree ways forward. They were seen as key mechanisms for working together, helpful because professionals were in contact with each other, and focusing on reaching a workable plan with clear duties and responsibilities. Practitioners experienced them as helpful because of "the level of anxiety such cases generated for managers and for workers" and because of "seeing obvious need that somehow you just cannot seem to meet because somebody appears to have capacity and they make an unwise decision or you are unsure about their capacity." Thus case conferences or panels got people talking about issues in cases and possible interventions to resolve them. They "spread the decision making" and "pulled everyone together into decision making". They coordinated the work effort rather than allowing a situation to persist where individual agencies were pursuing their own interventions, sometimes in ignorance of what others were doing.

Care agencies needed to be tied into these arrangements so that they could comment on how difficult they were finding it to work with a particular case, even to the point of believing that they should hand it back to adult social care. Equally, in conferences or panels, commissioners and other involved professionals could hear about the persistence with which care workers were visiting and not gaining entry, or about the limitations imposed by "15-minute visits". Rather than care agencies soldiering on or terminating involvement without much notice, panels or conferences were the means through which their experiences could be shared and action planned.

One manager also commented on the "loss of community involvement" in adult social care, and observed that panels and conferences should consider how to involve neighbours and community members in appropriate cases. Indeed, self-neglect SCRs have also commented on the involvement of the community and neighbours in supporting some adults at risk, and how they held information that was not being accessed by statutory agencies (Braye *et al*, in press a, b; see also May-Chahal and Antrobus, 2012).

The involvement of solicitors or CAB (for welfare benefit advice) might also be important depending on the circumstances of the case. Whoever was involved, good practice was seen as revolving around the sharing of risk assessments and action plans that sought to minimise the assessed risks, consideration of the legal options available to different agencies, and the circumstances in which these mandates

might be used, and the circulation of agreed notes and decisions, with progress chasing by whichever agency or professional was given lead responsibility. Jointly chaired panels, for example, between the police and adult social care, were seen as modelling good inter-agency working and as being more useful than a single agency lead.

If not case conferences, regular meetings of professionals were seen as helpful, the composition depending on the nature of the case. Pulling in relevant teams and agencies, accessing expertise from housing, health, psychology, psychiatry, environmental health and fire and rescue, for example, could enable feelings to be shared about the perplexing nature of self-neglect and unblock a complex case. Thus, in one case with a positive outcome, the meetings of professionals were used to explore understanding of a case, to support the one worker who had been able to engage the service user, and to agree how agencies would respond:

“One particular woman we had, who had functional mental health problems ... was going to lose her tenancy so [one worker] spent time going round and round there, trying to catch her in ... it was perseverance and eventually doing clean-ups and monitoring that with her, so persuading housing colleagues not to evict her.”

In those local authorities that had adopted a VARM system, these multi-disciplinary and multi-agency meetings were seen as operationally effective in self-neglect cases. Examples were given where they had prevented threshold bouncing due to restrictive interpretation of eligibility criteria for services, where they had explored risks and how agencies were managing them, and had identified who was involved and what they could contribute to an action plan. The meetings, chaired by senior managers in particularly complex cases, enabled the composition of a clear picture of what professionals and agencies were doing, which organisation had responsibility for what, and when they would normally intervene.

4.2.4 Compliance with guidance

Examples were given where procedures had been helpful operationally, for example, in securing attendance by different agencies and professionals at case conferences. However, there were also examples given where agreements had not proved sufficiently strong or enforceable. Psychiatrists and psychologists were reported by one manager, for example, as holding critical information about adults who self-neglect, but being very reluctant to share it, with a consequent impact on the comprehensiveness of assessments. Some managers emphasised the importance of practitioners escalating concerns when agencies or individual professionals were not engaging in multi-agency working and honouring the commitments as expressed through LSAB agreed procedures. Thus:

“We have got an agreement from senior managers that if we’re struggling to engage somebody ... we can go to them and they will engage the person, or engage that team on our behalf. So we very much operate on having relationships with key people. Occasionally I’ll find somebody and think, ‘I haven’t got a way in there,’ and I need to go round and knock on the back door and say to somebody, ‘get me in there, I need to talk to X.’ If you asked me to map out for you how that turns out in relation to the Safeguarding Board, I think there’d be lots of question marks. But

on a case-by-case basis, simply because the fact that the people who are in the office have been around a long time, and we have relationships with most people, and we know a man or a woman who can, we can normally join the dots to get a good appropriate set of people around each individual case.”

4.2.5 Effective engagement with adults who self-neglect

Managers gave examples of when they had worked with adults who self-neglect or when they had supervised the work of practitioners. What emerged strongly was that work was more likely to be effective when thought was given to how one engages and how one demonstrates professional values such as respect and dignity. The work was viewed as beginning with, and having to prioritise, trust and relationship building with people who are resistant to accepting any type of care. This could mean “revisiting and revisiting, and talking with them ... with cases like that you need to make the time. Otherwise there’s no point.” It could mean showing “real persistence” in seeking to develop a relationship, get across the threshold and begin to effect some improvements in someone’s living situation. It could mean sharing one’s recording with a person who uses services in order to facilitate discussion of needs, concerns and risks.

Examples were given where practitioners had gone shopping or to the cinema or the pub in order to build up a trusting relationship, because that was doing something that the individual liked. Other examples were given where this had resulted in people accepting help, both from the worker concerned, but also from other professionals, such as care workers, a GP or a district nurse, introduced by that practitioner. What had been learned through this process was “doing things with them that they like” in order to build up a relationship, and “making sure that you don’t force them into anything they are not prepared to.” As one manager commented: “It is just to work in small steps at a time, using your social work skills.”

For some managers, this approach was linked to a duty of care that emanated from their own professional practice and experience. It was tied into trying to improve outcomes for people, which involved “continuing to try and engage that person”.

“It would be very easy to say that person is not engaging, therefore we’ll close the case. I’ve seen that, I don’t think that’s good enough.”

In one case, where an adult was being financially abused as a result of giving his bank cards away to friends and callers, and whose house was filthy, the professional who got across the threshold was a member of the Safer Neighbourhood Team. This enabled other workers to improve the condition of the house, including making the front door more secure. However, the case was then ‘put on review’ and finally closed. Within six months there were further alerts expressing concern that this vulnerable person was being exploited, leading the manager to conclude that:

“There’s not a lot you can do other than keep it open and maintain that relationship going, but of course the pressures of keeping an ongoing case going like that is very hard in the community team that’s number crunching.”

The advantages of a gradual approach were described:

“First thing, obviously we would be looking at an assessment and we would be looking at what the risks are. And from that, we would then look to see how we can minimise those – we start to actually get carers involved, get involved in a befriending type way, try to build a relationship, very person-centred care where we can and that can be anything from just a knock on the door to start with, saying ‘hello,’ even sometimes we’ve had experience of [talking] through the letterbox. But as time goes on, we slowly will actually get in and then we slowly start to introduce others.”

Effective engagement required thought to be given to who might be best placed to secure engagement. Sometimes this might be fire and rescue staff, who could be perceived as less intimidating or threatening when offering advice and support to minimise fire risks. Or it might be an adult social care worker:

“It depends on really what the situation is; obviously a lot of our customers either have a functional mental health problem or they have a dementia illness and it very much depends on who can establish that relationship, and sometimes it is a social worker or community care practitioner to start with, who then take along a colleague, which could be somebody within the care provision. We can do anything from a knock on the door to then slowly getting in and slowly trying to make a difference within the home.”

Effective engagement and intervention was also based on a willingness to express concerned curiosity. Rather than say, ‘it is not for me to judge’, which would result in overlooking a duty of care to that person, managers recognised that it was important to ask questions around why an individual lives in a particular way, and what might have happened in that person’s life to have led to the circumstances they now find themselves in. This recognises the influence of a person’s history and the challenge of “dealing with the consequences of that today”, the need to balance respect for private life with a duty of care, and offer a range of possible services in order to respond holistically to the individual. For this manager, seeing the person holistically meant looking beyond the leg ulcers or the piles of comics being hoarded and asking questions, such as “how would you get out in the event of a fire?” or “what has led to you choosing to live in this way?” This line of questioning, in search of causes but also being prepared to point out possible risks and looking to see if people could manage the consequences of their decisions, involved skills that “professionals sometimes do not use often enough.”

“It’s around the respect for somebody’s wishes and feelings and choices, if they have the mental capacity to choose not to engage, versus our duty of care to ensure that we’ve at least asked and offered if they would like additional services, including mental health services. So even if they don’t want what we’ve got to offer ... would that person benefit from being offered assistance around the home, mental health services, GP and any of the other more holistic ways of working? So it’s not just about a single agency, duty of care, it’s just thinking about that more holistic approach.”

Vignette: John

Here the social care practitioner, working slowly and taking small steps, mobilises a network of acceptable supports from healthcare and community support, as well as charitable organisations; the provision of practical and tangible benefits build over time to acceptance of greater levels of support.

John is a man in his fifties to whom offers of support had been made over many years. His living conditions were squalid; his bed was a filthy mattress on the floor with bedding unwashed, and his personal appearance dirty and unkempt. Police referrals were frequent because he had ‘friends’ who would enter his home and take money from him, leaving him without funds to eat.

After a capacity assessment had determined it was his wish to live as he did, it was decided at a health and social care practitioners’ network meeting that adult social care allocate a worker more time to build a relationship with John. The worker liaised with community support officers to keep a watching eye on him; he sorted out John’s finances, and identified a health condition, which resulted in John registering with a GP and receiving healthcare. A new bed and bedding were sourced from charities. Over time, he was persuaded to accept a small care package involving a daily visit from a care worker who can report back any concerns, and he is now considering a move to sheltered accommodation.

4.2.6 Staffing

Managers also reflected on the knowledge and skills necessary to undertake work with adults who self-neglect. Some recognised that not everyone could work with this group of people who use services but the recognition was captured in different ways. One manager reflected on the need to:

“... employ some quirky people! If I think about the workers I’ve managed over many years who have had really good outcomes with this client group, they are not your average social worker actually ... you almost need people who are not afraid of coming at things from a different angle, of going the extra mile of relating to people in a slightly different way.”

This manager reflected, too, on approaches that were helpful in particular cases and services that had been lost over time:

“She would just go round to people’s houses at a different time or a weekend, and actually she seemed to have more success doing that because she found them at home; it’s a bit like assertive outreach in a way, you turn up at times when people aren’t expecting you or different times, and she had no problem putting her rubber gloves on and just doing the washing up – she wouldn’t say ‘that’s not in my job description’ – or clear the fridge out, very practical. You can social work people to death but actually what works are the very practical things because what users used to say to me was, in consultation events, ‘I can’t focus on my mental health if I’m in debt, if my house is falling down around my ears, my relationships are all over the place, if someone can help me crack some of that, I can then focus on what you want me to focus on’. Maybe working with this group is a little bit about going backwards and looking at some of the things that used to work a long time ago.”

Since the work was acknowledged as being “emotional and very challenging for staff”, management support through supervision was essential. This was seen as an opportunity for staff to come and talk through cases and the dilemmas they presented. Some managers described themselves as “very hands-on” in terms of knowing about cases and even undertaking joint visits to help with need, capacity and risk assessments. Some clearly expected their team members to flag up concerns about self-neglect cases on the basis that frontline practitioners should not be expected to carry all the frustration and anxiety when working with very high-risk cases where those referred could end up seriously ill or dead.

Supervision was also one opening where there could be a focus on health and safety, recognising that staff could “get worn out” due to stress, or could neglect the risks that they might be running because:

“... their focus is always completely on the person that they are providing the service for. Very rarely do they look at themselves and it stuns me beyond belief. It doesn’t surprise me that social workers have been injured, that they go off with stress ... when you look at the abuse they take over years sometimes.”

Risk assessment should focus as much on the workers as on the components of the self-neglect scenario being managed. This might involve managers challenging family members and laying down firm boundaries in respect of their behaviour towards a worker. It might involve using wellbeing assessments to check out whether there are workload pressures or other issues affecting performance at work. One manager captured the anxiety that can be present in the professional system, and recognised the need for staff support but also consideration of all available options.

“I think there is always a fear factor ... despite all of those [risks], he will not have us anywhere near him apart from, ‘Are you okay?’ But ... he is saying we’re harassing him. He potentially is someone who we will find deceased in his own property at some stage. It’s very difficult to know what else we can do. He’s had numerous assessments of his capacity and he is a capacitated man and he lives in very squalid conditions. It’s a difficulty.”

This emphasis on supervision was also accompanied in some interviews by the promotion of the use of team meetings to look “at something that is important to us.” The emphasis here could be on sharing learning from a case, problem solving, reflection or “real-time action planning”.

4.2.7 Mental capacity

The complexities surrounding mental capacity exercised managers greatly; whether or not a self-neglecting adult had capacity was “that critical point decision”. Managers had found, through case file audits, observed practice and commissioned SCRs, that mental capacity assessments were a difficult area for people to become and feel competent in, the more so if they were not called on to complete them regularly. One manager thought that the rigour and thoroughness of mental capacity assessments was variable, and had developed toolkits and offers of support for those practitioners who felt daunted by the task. Thus, in response to a question about the quality of capacity assessments and best interest decision making, another manager responded:

“I think they’re improving; people have training, there’s a lot of discussion, checking out and reflection; we’re fortunate to have a DoLS assessor within the team from whom we seek advice often.”

Finding that someone had capacity to take particular decisions could also lead professionals to conclude that nothing could be done, because people had a right to take unwise decisions, even when those decisions impacted on other people, and even when particular legal mandates might permit intervention. Put another way, a finding of capacity could act as a block to the consideration of other options and be used as a tool to dispose of cases.

“When that was all unpicked, a lot of the questions were around what housing were doing because when neighbours were spoken to, they were saying ‘we told you months ago that there were vermin, there were flies, smells, it was impacting on everybody and, in your landlord role, you’ve done nothing about it’.”

So, managers wanted a “cast iron understanding” in a case, drawing on medical history, social care records and experts on mental capacity, DoLS, mental health and/or best interest decision making as a second opinion or a sounding board. Concerns were expressed about the blanket statement “s/he has got capacity” without it being clear for what, to make what decision. Managers wanted more precision in discussions about capacity, which could be derived from skilled interviewing and an understanding of executive capacity. Skilled approaches to interviewing might involve the use of circular questions, a ‘show me rather than tell me’ approach, and the use of ‘concerned curiosity’. This might uncover, for example, whether an individual had learned how to present themselves as having capacity. It might also, coupled with an understanding of executive capacity, reveal a person’s understanding of the risks involved and their ability to execute and deal with the consequences of a decision. Getting this initial assessment process right, ensuring its thoroughness, was crucial to the unfolding of the subsequent care pathway.

“The main thing in trying to work with hard to engage people is always thinking about how safe they are, because we do come across a lot of self-neglectful people, they’re hoarders, their houses sometimes are so uninhabitable so the first thing is how

safe they are – carry out risk assessments, mental capacity, because they have a right to choose how they want to live but it's how we help them to make those decisions and how we work with them, in order to ensure their safety."

"It's that definition of self-neglect, isn't it? Is this a lifestyle choice? Is this the way a person's always lived? Are we clear that there isn't something else going on in terms of their health?"

Thus, personalisation did involve choice and control, "to enable a person to live as independently as possible". However, it did not mean failing to discuss risks and how to keep people safe. Nor did it mean a failure to question and interrogate the impact of mental distress, loss and trauma on decision making. Nor, for managers, should it excuse a failure to involve other professionals as a means of monitoring situations where a capacitated adult reached a decision to refuse particular interventions, such as medical care for ulcerated legs. Put another way, some concern was expressed that personalisation, positioning the person who uses services as the expert, had led to the erosion of social work expressing its knowledge and using its skills authoritatively.

In the view of managers, the question of capacity was more effectively handled when professionals were clear about the impact of values, such as personalisation and autonomy, on how situations were seen and options envisaged. Equally crucial was the importance of the professional network being clear about which legal options were available in what situations.

Closely connected with capacity was the question of whether an individual had consented to a particular intervention and, if consent had been secured on one occasion, whether it needed to be confirmed on each subsequent visit. This led one manager to recognise the need to understand a person's emotional frame of mind on each visit, which might make the dressing of leg ulcers or some other aspect of personal care more or less acceptable. Equally, the worker had to recognise their own emotional state and the impact that this might have on a face-to-face interaction, especially if feeling under pressure because of the volume of work needing to be accomplished that day.

4.2.8 Levels of legal literacy

Managers themselves sometimes appeared uncertain about the available legal rules and/or experienced barriers to accessing quality legal advice. For example, one was uncertain about whether the Court of Protection could hear cases concerning people with capacity, leading them to conclude that further legal updates were overdue. They also noted that legal knowledge that was not often used, such as inherent jurisdiction and declaratory relief, was difficult to retain. Another manager acknowledged that they would have to find out about legal options when someone was refusing an assessment when self-neglecting. They were unclear about how the law with which they were familiar, especially mandates for community care and mental health assessment, might apply. In referring to the interface between mental health and mental capacity legislation, one manager said that they had been on "an interesting learning curve".

However, while acknowledging the conundrums that cases of self-neglect could throw up when the person concerned has capacity, others nonetheless knew of cases where local authorities had used the Court of Protection for vulnerable but

capacitated adults, and had included this option in their safeguarding policies and procedures.

Equally, they observed that practitioners and managerial colleagues could also find the law daunting in its complexity. This finding has also emerged in other research (Pinkney *et al*, 2008; Preston-Shoot and McKimm, 2012). One social work manager described a safeguarding lead colleague from a health background as not having the conceptual or legal framework that a social worker would have, and misconstruing key parts of the Mental Capacity Act 2005. Another acknowledged that complexities arose when “someone’s saying no” to an assessment. A third believed that people “were struggling to understand that capacity is specific and quite often they will generalise and use that as the reason they move on. The Mental Capacity Act is still not well understood”. Thus:

“There is obviously the Mental Capacity Act if that applies; it’s when people clearly appear to have retained capacity under self-neglect and that’s when we are struggling and it is not something that as an authority we have got a very good hold on in terms of the powers that can be used.”

Another example follows where the legal rules were experienced as difficult to understand. Thus:

“Because the legislative framework’s quite clear around that, once you’ve made that decision, that they don’t have capacity, staff seem to work quite well with that. I think there are still challenges with the police sometimes and with ambulance, particularly when it comes to moving somebody from A to B, but they work with it and they work quite well with it. I think the difficulty for people is when they’ve made that decision that somebody does have capacity.... I think the legal framework around that is far less clear. It’s not clear to me. So how it’s clear to them I really don’t know and certainly when you start talking to GPs, district nurses, police, ambulance service, if they’ve got capacity, unless a crime’s been committed and that’s obvious, the lines are fuzzy and everybody takes a step back really and it does feel sometimes like adult social care get left holding the baby.”

Equally, managers had experience of being over-ruled by their own managers with respect to pursuing particular legal options, leading one to conclude that:

“It became quite evident that the issue was around capacitous adults who are self-neglecting; there’s not a lot of thinking on it. In fact, people use the Mental Capacity Act as, if you like, a road block.”

Nonetheless, there were examples of where guardianship under the Mental Health Act 1983 had been considered, although it was rejected in one case as, while it would allow the local authority to get the individual to reside in, and return to, a particular place, it was judged not to help in meeting other needs that were in the individual’s best interests. Provisions in the Mental Capacity Act 2005, such as applying for deputyship, were occasionally reported as having been used, as was compulsory admission into psychiatric wards using assessment and treatment sections in the Mental Health Act 1983. No one had used Section 47, National

Assistance Act 1948, although it had sometimes been considered. Environmental health officers had been engaged in a few instances when cases were extreme in order to access their legal mandates. As has been found in other research (Doel *et al*, 2010), reference to human rights law was implicit rather than explicit.

Although legal mandates were seen as having their place among interventions in cases of self-neglect, and had been found to be very useful in particular cases, some managers expressed reservations about too early a resort to statutory mandates. One suggested that legal rules provided “short-term fixes rather than long-term cures.” Another hesitated because in their experience “the more you push, the more resistant they become.” Another worried that relationships could be damaged to the point of losing any engagement at all because people would feel violated. Resorting to legal options, then, might

“... enable a local authority to compel an individual to change in ways they do not want to, so it is easier for the authority because they have the power, but it is not necessarily easier in the long-term engaging and bringing about change for somebody.”

This led managers to stress the importance of relationships as much as legal rules, and being clear what standards practice is aiming for. These were defined in various ways but included putting the person who uses services at the centre of focus, with legal authority and good practice running together, “trying to get away from just thinking what we can do legally but to help them think a bit more about how do we build that relationship.” It included being clear what ‘good’ looks like, and ensuring that documentation to support decision making in a case was sound. It took some managers back to underpinning principles for social work practice, and to wanting to humanise the process by person-centred practice,

“... being flexible around case conferences, bringing the individual or an advocate in as far as it is practicable and reasonable, giving validity to everybody’s views but at the same time being clear about ‘where we are viewing this from?’ and taking practical steps to put the individual at the heart.”

This might not avoid recourse to the law in extreme situations of hoarding or squalor, but arriving at that point should not be at the expense of opening up issues with people who use services and exploring the choices that they are making.

What emerges is that managers are concerned that workers are too reluctant to use the law where people have capacity. Equally, emphasis emerges that the key challenge is appropriate use of the law rather than thinking of it either as the ‘first’ or ‘last’ resort. Indeed, other research (Preston-Shoot and Cornish, 2014) has found that workers can use the legal rules within adult safeguarding proportionately, with due acknowledgement of human rights and in partnership with people who use services.

4.2.9 Effective interventions

Components of effective interventions with adults who self-neglect therefore emerged from the interviews with managers. These included the importance of time and of flexible organisational structures rather than the imposition of strict rules about case holding. Equally crucial appeared to be continuity of relationship rather than transfer of cases at fixed points of time, and recognition that this was skilled long-term work. The lead practitioner might well be the individual most likely to be

able to engage, who might be a male rather than female carer, a healthcare worker rather than social worker, or a volunteer or neighbour.

Vignette: Marjorie

Here the focus was on finding the right person to engage with the individual and make a connection through an activity that fitted well with the individual's own interests; through that connection was built a relationship that provided a bridge to the provision of more formalised support.

Marjorie was struggling to care for herself and to look after her property, the neglected state of which posed serious health risks. She refused to let professionals into her home, and declined services; she didn't go out, and had no social contacts. But, as a former writer and journalist, she loved to read, so she had a good relationship with the person who delivered books from the mobile library, because they brought her something positive.

Environmental health action or use of eviction powers were being considered, but the agencies involved were reluctant to embark on action that Marjorie would find frightening. Instead, adult social care engaged the mobile library staff in working to help keep Marjorie safe, because she was the person who could always get through the door, whereas everyone else struggled. Through stretching that relationship, in consultation with adult social care, the librarian was influential in a support plan that Marjorie could feel positive about.

The ability to see the individual holistically and to respond to the whole person was seen as important, where necessary lowering thresholds in order to assess a person's needs. Concern was expressed that agency and individual worker specialisation meant that they only focused on what they believed to be within their role and remit.

"She will only accept help at home from one care manager and although that care manager wasn't really at times in that particular team that was dealing with the case, we've had to keep that one on because she's the only one that she would allow in because if you go in and you've got different colour eyes ... so in the long run, we've had to keep this particular worker working with her."

"So, as managers, it's allowing that time for the social worker, because you could go back 10 times and not get in! It's the perseverance, so I think as managers we've got to be a bit mindful that they're not quick turnover cases and sometimes you're setting action plans and you need time for those action plans, so that's like the next one, another meeting, so they are time-consuming but you have to invest in it."

Accordingly, convening the system, whether in multi-disciplinary meetings, panels or case conferences, was an effective way of reviewing the risks, identifying how single agencies had been approaching the case, exploring legal and other options open to partners, and coordinating action.

As one manager observed,

“... the last thing someone may want is half a dozen people coming round ... so it is not necessarily about mobilising all those staff to come and work with that person but it is about sharing knowledge and skills.”

Whatever was decided on required accurate recording (with reasons for what was decided to be within and out of scope) and dissemination, and then active follow-up and review. Where a self-neglecting adult continued to refuse to engage, active monitoring as the only available option to seek to minimise risks was more appropriate than case closure and withdrawal.

This work, however, requires skilled interviewing and authoritative but respectful challenge rooted in concerned curiosity. One manager thought that authoritative interviewing meant pointing out the risks to others, such as neighbours, where relevant, and seeking a negotiated settlement along the lines of “you would return home more safely if...” Describing a situation where a woman was self-neglecting and living in an emaciated state, with a husband who might have been neglecting rather than attempting to care for his wife, another manager said that:

“There are times when you have to weigh somebody and you have to check what their nutritional status is, it’s no good when somebody’s just lying with a sheet up to their neck all the time, to accept that what’s being said is actually true. It’s about challenging – it’s difficult, very difficult to do.”

Also raised was the importance of prevention and early intervention. Here community police officers, utility companies or GP surgeries might be examples of professionals who can spot the first signs of self-neglect – the state of gardens, the failure to collect repeat prescriptions. Tenancy sustainment and flexible dementia services might then be examples of work to maintain people in their own homes where possible.

4.3 Conclusion

The managers were fully cognisant of the complexity of self-neglect cases and of the ways in which interaction between the themes identified above can help or hinder positive outcomes. The most constructive work was, in their view, characterised by respectful and authoritative challenge, constructive use of case conferences and case discussions, creative engagement through careful consideration of the most appropriate channels, the operation of flexible thresholds and full consideration of legal options. Often key to moving a case forward towards positive outcomes was the strength of inter-agency commitment that can be secured.

One manager advised that those working with adults who self-neglect, and their organisations, should focus on striving for “little victories” as much as outcomes. Ideally, this meant working towards a win/win position for the person who uses services and the local authority rather than one having the “upper hand”. These little victories were reported in the course of the interviews.

Thus:

“One of those individuals has had no services for two years and is fit and well and happy and another gentleman periodically disengages from services, but we think we’ve got him to a position where at least we feel he’s safe because he does get responses from the ambulance service, he does get responses from mental health now – he is somebody that periodically does need support from mental health services and he wasn’t getting that previously. So I think that’s been the benefit, as far as I can see.”

These little victories required considerable persistence and skill from staff in order to encourage someone who self-neglects to engage, to talk about the origins of their behaviour, and to allow care-giving. It also demanded flexibility in terms of organisational structures as well as ownership of responsibility for the whole person from each of the agencies and professionals involved.

5. The perspectives of people who use services

Each of the practitioners interviewed for this study was asked if they knew of people who might be considered to be in a situation of self-neglect, or to have self-neglected in the past, and who might be willing to speak to a member of the research team. Inclusion criteria stipulated that they must have capacity to be able to give informed consent, and that the interview would not be likely to have a negative impact on their wellbeing. As when interviewing practitioners, no specific definition of self-neglect was imposed on the selection, and it emerged that those approached understood the term in a range of different ways. Indeed, some felt that they could not be considered to be in a situation of 'self-neglect' and did not agree to participate in the interviews for this reason. It is perhaps unfortunate that the reasons why those who refused held different perspectives from the practitioners who worked with them could not be explored, but the researchers were, of course, ethically bound to respect their choice.

Twenty-nine people who use services were finally interviewed, along with two family carers who also wished to give their perspective. Their situations are diverse, illustrating the range of forms that self-neglect can take and the wide variety of challenges that it may pose. Eight of these interviewees were individuals with whom the practitioners interviewed had worked directly, permitting a degree of triangulation between their complementary perspectives. A significant proportion of those interviewed were in contact with support services at least partly as a result of hoarding. Another sizeable group were accessed through homeless support services, while the others were for the most part contacted through care management teams. It cannot be claimed that this sample is a representative group of the full range of people in situations of self-neglect, nor was it intended to be – rather, it is a purposive sample, selected by practitioners working to resolve self-neglect issues, of those who may be in a position to shed light on the challenges they faced, and what they found to be effective or less effective from the services working with them. It is worth noting in this regard that many of the stories told by these service users, even though they were selected by practitioners as potentially being able to tell us about good practice, were by no means wholly uncritical. In exploring what constitutes good practice in self-neglect, it is important to learn lessons from what may have been experienced as unhelpful as well as what was successful.

5.1 Self-neglect among the interviewees

Taken as a whole, the interviews confirmed that there is no 'typical' self-neglect case. Stark contrasts clearly exist between those neglecting their home living environment and those living on the streets who may be neglecting themselves, but there were also significant differences even among those whose situations might superficially seem to be similar. For example, while the label of 'hoarder' might be applied to many people in this study, they accumulated different things, in different ways, for different reasons; as one person put it, "All hoarders are individuals with individual reasons." The same sentiment was expressed about neglect of self-care:

"You can't exactly do this sort of thing with psychologists. Each person is individual, so you can't do a quantitative assessment as it were, it's got to be a case-by-case study. So you can only treat people as they come along, that's roughly about it."

While a detailed account of the forms of self-neglect encountered in this study, and the factors contributing to it in each case, is beyond the scope of this research, exploration of what those who use services said about how they had come to find themselves in the situations described will show the need for flexibility of response to self-neglect on the part of practitioners and services. It would have been overly complex to attempt to present a detailed typology, but – following a split commonly found in the research literature (Braye *et al*, 2011a) – the analysis distinguishes between cases where failure to care for the self is the primary concern, and those where failure to care for one's surroundings is the primary concern. Although a single interviewee sometimes displayed signs of both, most often one or the other was dominant.

5.1.1 Neglect of self-care

Interviewees variously spoke of how they neglected their hygiene, appearance, health and/or emotional wellbeing and needs. Some did not wash or change clothes for long periods; they either stopped noticing or stopped caring about their smell or cleanliness. Some neglected to take basic health precautions; they might eat rotten or mouldy food, fail to take prescribed medications, or take common steps to protect their safety, with sometimes quite serious effects on their wellbeing. Some placed emphasis on how they neglected their emotional needs, leading to further despondency, and often contributing to failure to care for other areas of their lives. In some cases, alcohol or drug addiction was intertwined with the self-neglect, as either a contributing factor or a consequence. Ten interviewees were currently, or had previously been, living on the streets; a few told stories that suggested that self-neglect may have contributed to this, but most saw self-neglect as a situation that had followed on from homelessness.

Six overarching themes could be identified in what the interviewees said about the causes of their neglect of self-care: 'demotivation stemming from other factors', 'other priorities', 'different standards', 'maintaining self-care', 'uncertainty about reasons' and 'inability to self-care'.

Demotivation stemming from other factors

Interviewees commonly spoke of how their self-neglect was a direct result of demotivation. They pointed to aspects of their lives that made it seem almost meaningless to attempt to maintain a typical self-care routine. One person spoke of how,

"I'm drinking, I'm not washing, I wouldn't say I'm losing the will to live, that's a bit strong but ... I don't care, I just don't care. If I wake up smelling, so what, I'm not going to find a girlfriend or a job 'cause I ain't got nowhere to live, why do I care? But I do morally, but ... day-to-day life, so what? I try my best but...."

Many others echoed his sentiments. Health difficulties, homelessness, loss and social isolation were repeatedly cited as reasons why self-care had come to seem comparatively unimportant. This in turn could impact on self-image, further demotivating them and entrenching negative cognitions: "I would sit here and not even have a wash. I got it in my head that I'm unimportant, so it doesn't matter what I look like or what I smell like." As he received few visitors, he had come to view his self-presentation as unimportant, but this interview revealed how an apparently reasonable reaction can belie deep feelings of worthlessness and despair.

Other priorities

Another common feature of the accounts of people who use services was the idea that their self-neglect was the result of putting other priorities first. For some, this might be expressed in general terms:

"I wouldn't bother to wash and no, I haven't this morning either.[...] I don't bother washing up, I'm out [of the flat], me.[...] I seemed to have plenty of time to do everything but I don't seem to have the time now."

Others were more specific about why self-care came some way down their list of concerns. Frequently, it was stated that they self-neglected because they habitually put others first: "Everyone else to me came first and I think that's what – I kind of neglected myself on and off for 10 years, putting what I wanted on the back burner." One person had been a family carer for some 20 years with little, if any, support, before becoming homeless:

"I always neglected my own feelings for instance, and I didn't address them, didn't look at them in fact, I thought 'no, no, my feelings don't come into it', she's more important and I literally ... my life was surrounded with whatever she did, and 24/7."

Against stereotypical views of self-neglect developing when individuals find themselves socially isolated, as in the quote relating to demotivation above, these interviews showed how it was sometimes the result of a pattern of prioritising care for others.

Different standards

The interviewees sometimes suggested that what constituted acceptable self-care for them differed from what was more commonly accepted within society. This did not necessarily mean that they insisted that their own view was correct; rather, they put this forward as a way of making sense of how situations of self-neglect had first arisen for them. For example, one individual said of his disregard for washing and general hygiene: "I wouldn't say I let my standards slip; I didn't have much standards to start with." Another spoke of how people often mistakenly thought he was homeless, because of his indifference to social judgements about his appearance.

Maintaining self-care

The interviewees also pointed out what they were doing to maintain self-care, rejecting the idea that self-neglect had come to define their lives. One person commented that "I'd always keep my clothes clean, but not necessarily myself – very peculiar and once again it's like a mental block." While she placed emphasis on the difficulties she experienced in aspects of self-care such as washing herself, she also showed that she continued to manage in other areas. One man spoke of how he partially overcame both practical obstacles and demotivation to keep up appearances, although this was only possible to a degree:

"I try my best, really do, but there are days where you just [...] I could walk down the street now and people would never know that I was homeless unless I took my clothes off and I'd be fucking minging, because I have lost that will to, not will but..."

Although others, and to an extent they themselves, might think that they were self-neglecting, it is important to recognise that this was not the whole story.

Uncertainty about reasons

It was striking that only one interviewee expressed real uncertainty about how she had come to find herself neglecting her self-care. When asked about this, her response was, “Well I don’t know to be honest. Suddenly one day you think, ‘What am I doing here?’” Probably this was at least partly due to the fact that she had been diagnosed with Alzheimer’s disease, which would account for both the self-neglect and the difficulty she had tracing back how the situation had developed; she may also have preferred to avoid going into detail out of a degree of embarrassment. The stories of other interviewees expressed fairly clear accounts of how they might have come to neglect their self-care, even where multiple factors and possibilities were suggested. This doubtless reflects an element of self-selection, given the fact that they were unlikely to agree to be interviewed if they felt they could not offer a useful narrative, but also serves as a reminder that self-neglect often does not mean that individuals necessarily lack awareness or reflective capacity.

Inability to self-care

While this theme often co-occurred with that of ‘demotivation’, it emerged in its own right within some interviews. Mental health problems were one reason why some felt unable to maintain self-care; one person described how, following her “breakdown”, self-care

“... makes me tired, very tired, and people who don’t have it don’t understand.[...] I get tired because daily routines are exhausting me, to do the simple things like get washed, put on clean clothes, wash my hair.”

Although she highlighted the small successes when she would manage to keep up aspects of self-care, the significance of such obstacles came through clearly when talking to her. Physical health issues were also sometimes mentioned as making aspects of self-care difficult. For some of the interviewees who were homeless, adequate self-care seemed equally challenging, if not impossible, as a result of their circumstances. One individual put it particularly forcefully:

“So once you’re mentally neglecting yourself, ie, you’re homeless, not getting the amenities, you’re not getting the support, then yeah you are going to fall to bits. I don’t even know your name, that doesn’t matter but if you were in my position, you would do exactly the same as anyone else in this building. Your mental – it would lower itself, your esteem, everything about you, you lose your way, your jeans are dirty, you have to buy crap jeans, so now you’re lessening yourself as the way you dress, so now you’re demeaning yourself as the person you knew you were and then in the end, it’s the physical neglect. You can’t wash because there’s nowhere to wash, you can’t be nice and tidy because you look like shit because you’re literally sleeping in what you’re sleeping in, how do you get someone out of that?”

At moments like these, the interviewees questioned the extent to which they had any control over their self-neglect.

More than one theme often emerged over the course of a single interview, reflecting the ability of the interviewee to put forward and explore different interpretations of their experience. From what they said, it seemed that more effective practitioners were able to understand the perspective being taken by the service user and engage in a responsive manner, as will be explored later, in Section 5.2.2.

5.1.2 Neglect of the environment

Within this sample of people who use services, hoarding was the most common way in which they neglected their surroundings. The extent of the hoarding varied. Sometimes it was reported to be limited to selected rooms in the house or flat, often as the result of pressure from other family members to prevent further expansion; at other times, the entire accommodation was described as knee-deep in accumulated possessions and/or waste. Still others said that objects filled nearly all available space within the residence, to the point where it was difficult – if not impossible – for people to enter, and ‘tunnels’ amidst ‘stuff’ were the only way of moving from one room to another.

Not surprisingly, these levels of hoarding often co-existed with a deterioration in the quality of the accommodation – as it became impossible to provide access for contractors to maintain heating, electricity or plumbing, or they simply refused to enter under existing conditions – and/or with the build-up of grime and decaying food or other waste, or risk of infestation, as it became more and more difficult to clean effectively. One man spoke of the “cat mess” found in his flat following a cleaning intervention, and how he “didn’t even know it was there”, partly as the result of the amount of material that had accumulated. Such situations also arose where hoarding was not a factor. Mild dementia had made it difficult for one person to clean herself and her apartment effectively and, although she was otherwise quite tidy, resulted in her accommodation becoming unhygienic, due to the accidental smearing of faeces. Meanwhile another, although he also hoarded items, found cleaning the kitchen difficult for reasons of mental health. Following a supportive intervention, he spoke with amazement of the difference that cleaning had made.

The perspectives expressed by interviewees on how and why they neglected their environments were no less varied and complex than those concerned with the neglect of self-care. A distinctive feature of this group, which was much less likely to be heard from those who primarily neglected their own self-care, was that they were more likely to see value in their self-neglect (while still acknowledging the harm that it caused). This finds its place amidst the themes emerging from interviews with this group of self-neglecting service users, which otherwise show many similarities with those above relating to lack of self-care. The four themes identified from the interviews with people who use services who neglected their environments were: ‘influence of the past’, ‘positive value of hoarding’, ‘reasons beyond interviewees’ control’ and ‘uncertainty about reasons’.

Influence of the past

A number of interviewees spoke about the significance of childhood experiences in shaping their present-day actions. For those who had lived through the Second World War or its aftermath, that experience was sometimes mentioned: “when I was a little boy, the war had just started, everything had a value [...] everything in my eyes then and indeed now, has potential use.” Others traced their hoarding tendencies to parental influence, whether directly (as with one person who said that

she had learned from her mother's example as someone who threw nothing away), or in reaction against it (as with another who was never permitted to keep toys by his parents: "the only way I kept toys was hiding them"). Another individual attributed his hoarding, the collection of particular newspapers, magazines and tapes, to attachment problems that had originated in childhood experiences and that were profoundly influenced by his parents' mental health issues. He had become "phobically attached to the home" and "avoided people".

For many, the hoarding had become a more significant problem when they inherited the possessions of deceased relatives and had never sorted through or thrown out any of them – sometimes out of a sense of loss, sometimes because they had not been able to make time. Some attributed their neglect of the environment to past events that had affected them deeply; these included traumatic events, such as parental psychological abuse or bereavement, and either affected their will to maintain their surroundings or led them to accumulate as a form of comfort.

Positive value of hoarding

Some interviewees disputed the labels that they felt were commonly placed on them and their acquisition of items. They preferred to speak of "collecting" rather than hoarding, and disputed health or social care reports that spoke of "rubbish". One pointed out that "It was not all rubbish, because I did object to that word. Fifteen tonnes of rubbish would have been no problem to detach mentally; it was the good stuff." He referred to a piece of furniture he had painstakingly made as a work of art: "we – people who self-neglect – we cling onto our triumphs."

Another felt that

"In my case the problem would be that there's a lot of stuff I would be willing and ready to get rid of [...] but the reason why I would have accumulated stuff [...] it's mainly photocopies, books, newspapers and I don't have time to make a note of everything in the paper that has an interest to me and so I'm very fearful of throwing something away."

Like him, many felt that what they acquired was useful to them, or – even if it had outlived its usefulness – that it was a waste simply to throw out things that they thought might still have some monetary value. For others, the value of their possessions was more psychological ("I want things that belonged to people so that they have a connection to me") or instrumental ("People know I might have things that they are short of, so I feel needed"). For one man, his hoarding provided emotional security and fulfilled basic needs. It was "a positive way to fulfil my needs; my possessions are my family." The importance that their "stuff" had for them is one reason why clearing cluttered apartments and houses is so often no simple matter for services.

Reasons beyond one's control

While nearly all interviewees who neglected their environment felt that it was in some way beyond their control, a few put forward reasons why they would not have been able to do anything about it, even had they been psychologically capable. For one individual, his childhood and adolescent experiences had left him with deep-rooted phobias and obsessional behaviour, with the result that "the distress of not collecting is more than the distress of doing it." For another, physical health problems were

implicated in her hoarding as they prevented her from bending down and picking things up, although she felt that psychological causes were also significantly implicated – and indeed, her care workers helped with domestic care, but their input had not been able to resolve the accumulation. One woman who was hoarding reported that she heard voices telling her to keep everything; although her medication went some way to keeping the voices under control, it did not enable her to clear her house. Other hoarders commonly blamed lack of living space for their inability to prevent their stuff affecting their daily lives at home, particularly if they lived in small flats: “If you’ve got a lot of things, like I have, it’s space”; “[The flats]’re pigeon-holes, to tell you the truth”. For some, this was certainly a factor among others.

Uncertainty about reasons

Not all interviewees dwelt on the reasons for their self-neglect. Some said instead that they “haven’t a clue” why it was so hard to clean and clear, or, on hoarding, “Don’t know. Don’t want to get rid of them, I want them, but that’s it, I don’t know.”

5.1.3 Emotional and cognitive responses to self-neglect

Most who participated in these interviews referred to the powerful emotional effect their self-neglect had had on them. The analysis above has already touched on how self-neglect could feed on demoralisation and demotivation arising from other issues in the service user’s life. The self-neglect itself might in turn lead to further demotivation: as one person put it, once self-neglect starts

“... then you’re not thinking, not like outside or what the possibilities are, ‘if I did this, I might get a nice girlfriend,’ ‘if I did this, I might get a nice job,’ ‘if I did this, I might feel better with myself’.”

One man described how he “used to wake up in the morning and ... cry when I used to see the sheer overwhelming state” of his flat, resulting from the extent of his accumulation. For another, to live with self-neglect was to feel

“Just lost, you just feel worthless, no self-worth, there’s absolutely nothing inside you, there’s no focus to doing anything, your whole shell’s just collapsed and it doesn’t necessarily have to be drink or drugs, you just give in mentally, physical. The life’s drained out of you, you see no hope and you just deteriorate, mentally and physically.”

A key element in the emotional response of many was their perception of how they would be perceived by other people. From the woman who, when she realised the extent of her self-neglect, felt that “people are not going to like me sort of thing – well they don’t, if you come out all scruffy,” to another who said that it was “not nice, not normal” and was reluctant to let anyone see inside her house, interviewees had the sense that self-neglect marked them out for stigma.

One individual used strong terms to express his sheer terror at the prospect of “my mess – and a lot of it was filth – coming to the public, well coming to anyone’s attention.” For him, even the experiences of wartime, although “scary”, were “nothing, nothing compared with what I was experiencing” when he thought about being “found out”, and although his flat had been cleared more than three years before the interview, he spoke of how receiving letters with a council heading still

provoked a residual nervousness – “post-traumatic stress” was the term he used to describe it. At other points in that interview, he emphasised that he did not generally care much about “concessions to society’s views”, which only serves to underscore how deeply and uncharacteristically distressing the thought of having his hoarding exposed had become. Like him, others had made efforts to avoid the attentions of the council. Some feared that they might eventually be evicted, or had had neighbours threaten to get them evicted.

One woman communicated what might appear to be a contrasting anxiety in her interview. Rather than fear of being found out, one of her concerns was that she was perhaps only too capable of covering up the extent of her self-neglect and people (primarily professionals, workers, or service managers) therefore did not realise how badly it was affecting her: “I wonder if [...] everybody thinks I’m okay, but I’m not okay – I’m very, very not okay.” This sentiment was partially echoed by another:

“I’ve recently met someone who doesn’t understand mental illness at all, which is different for me because most of my friends do.[...] This person doesn’t seem to get it at all, why I get so tired...”

For them being discovered is not the main fear, so much as lack of understanding. This resonates with comments by some interviewees (particularly those who hoarded) that they had felt like the only ones who acted so strangely, until the revelation of finding out that such forms of self-neglect were more common than they had thought.

5.1.4 Links to mental health, physical health and social relationships

Hence, although a constant feature of all these accounts was the far-reaching effects that self-neglect had within the lives of this group of people who use services, it took varying forms, gave rise to a range of responses, and perceptions of its causes differed from person to person. It is therefore unsurprising that the interviewees often linked it to their mental health, physical health and social relationships in complex and varied ways. This was a set of complex intertwined relationships rather than a one-directional process; self-neglect was identified as both cause and effect where issues arose in these three domains, which in turn fed into each other.

Mental health was closely identified with self-neglect. Some interviewees said that they had experienced depression, and that this either led to or exacerbated self-neglect, as it sapped their energy and motivation to care for themselves or their surroundings. There were times when, although interviewees had had no formal diagnosis, the language they used to describe their state of mind suggested that they may have been through depression in the past; a few explicitly discussed how their situation of self-neglect directly led them to question whether life was worth living. For example, “Honestly, it was just aimless. Sometimes I wish I’d never wake up [...], my God, sometimes I just don’t want to wake up anymore.” Apart from depression, other mental health diagnoses that featured in one or more interviews, and that were felt by the interviewees to have contributed to their self-neglect, included attention deficit hyperactivity disorder (ADHD), post-traumatic stress disorder (PTSD), Alzheimer’s disease, schizophrenia and obsessive-compulsive disorder (OCD); however, only three interviewees reported having spent time as in-patients in psychiatric hospitals.

Some described past or present alcohol misuse; they universally described it as a way of coping with or ‘self-medicating’ the issues that contributed to their self-

neglect. Among those who hoarded, some considered that this constituted a mental disorder (often as a manifestation of OCD), while nearly all had at some point considered – or been told by others – that they might be ‘crazy’. This might be resisted (for example, one man compared himself to the hoarders he had seen on recent television programmes, and concluded that his own behaviour was much less extreme) or accepted as a way of understanding the situation and accessing relevant help. One of the carers interviewed felt that from a carer’s perspective it was “quite useful” for the doctor “to actually put a label on [his mother’s] condition.” From his point of view, the diagnosis of Diogenes Syndrome (see Halliday *et al*, 2000; McDermott, Linahan and Squires, 2009) was something that could be researched, provided a framework through which to understand what otherwise simply seemed to be bizarre behaviour, and helped to justify the argument for social services input.

Some suffered from physical health problems that affected their mobility, confidence, self-worth and energy levels, and consequently their mental health and self-neglect. Self-care and care for their surroundings were hindered. Another aspect of self-neglect was that they might fail to follow their medication prescriptions, particularly if they were also depressed. Self-neglect had led some interviewees to fail to take steps to care for their health; the resulting deterioration or new diagnosis came as a shock that further worsened their tendencies to self-neglect. By contrast, many of the interviewees who were living on the street had health concerns that they felt they were in no position to do anything about, and were thus forced to neglect, unless they could access accommodation. Lack of shelter took its toll on them. For those who had their own accommodation, the environment could also be harmful. One individual described the damp, cold and mould in the house where he lived before he was admitted to hospital with leg ulcers and the house was determined to be unfit for him to go back to, but he said that when living there he had “got it into his head that I think that was where I was supposed to have been, that’s where it was supposed to have ended for me.” This quote illustrates how pernicious the combination can be when problems of physical health, mental health and residential environment come together with self-neglect to inculcate an attitude of resignation, even fatalism.

Significant relationships were sometimes reported to have kept self-neglect in check. One man spoke of how “if I didn’t have the wife that I have, I would be self-neglecting”, although he acknowledged that his accumulation of papers had meant that they had “been through difficult periods” and “harsh things” had been said. Another individual recounted how her hoarding had been more under control when her children were at home, but now there seemed no point in keeping up a routine of cleaning and clearing. Some interviewees had isolated themselves to a greater or lesser degree, largely out of reluctance to let anyone see the state of their homes, or had been pushed into self-neglect by the loss of social networks due to a move, bereavement or the end of a relationship. However, stereotypical images of solitary self-neglect were shown to be often wrong, for some were active in their neighbourhood and community, while others were regularly visited by relatives (themselves sometimes at a loss what to do about the self-neglect).

5.1.5 Implications

The interviews confirmed that people self-neglect for a wide variety of reasons. Practitioners should therefore be alert to the complex mix of factors that can lie behind self-neglect, which may involve demotivation or depression, standards of self-care that differ from the norm, physical or mental inability to avoid self-neglect, the

influence of the person's past, the positive value they attach to the behaviour, or still other considerations. Self-neglect may have significant effects on emotional mental health, not only directly, but in the sense of how others are perceived or anticipated as likely to respond – whether this is over-reacting to, or under-appreciating, the significance of the self-neglect and associated needs. It is thus important that practitioners approach situations of self-neglect in ways that seek to understand this complex mix of factors, and fully consider mental health, physical health and relationships within a holistic assessment.

Vignette: Barbara

Here, the practitioner has found practical ways to help in order to build trust and promote safer living, being flexible in responding to whatever the individual offers as a point of engagement; but she has also engaged with the more difficult emotional factors that underpin the reliance on alcohol.

Barbara, in her fifties, is a heavy drinker and smoker. She neglects her personal care and her diet, and her living accommodation is dirty and bleak, bare of furniture and of any comforts. She routinely falls when she has been drinking, becomes incontinent, and has been hospitalised with fractures and on one occasion, bad burns. She recounts how her relationship with alcohol has developed over years of difficult relationships, as an abused child, with partners (divorce and bereavement) and with her adult children (whose financial abuse of her resulted in a safeguarding investigation). She says she drinks to blot out the sense of loss and despair.

Services are aiming to support her in a managed drinking strategy, and encouraging her to improve her personal care, including a more nutritious diet, coupled with activities that will enable her to make stronger social contacts outside of her home to counteract the depressive effects of loneliness and isolation. Her worker has built a relationship slowly, offering practical help with furniture that was badly needed, and providing transport to enable her to attend a lunch club that will ensure she eats a meal. She has supported Barbara through her emotional distress and advised on ways of managing the very difficult dynamics that surround her family relationships.

Barbara feels that her worker takes the time to listen and that she understands what she needs to do for herself; there has not yet been a problem that she hasn't been prepared to help with: "she puts herself out for me."

5.2 Initial engagement

A key challenge highlighted by practitioners in the interviews, as well as in the research literature (Braye *et al*, 2011c), related to how willing people who self-neglected had been to engage with them and the services they could offer. Of course, since the group of self-neglecters interviewed was accessed through the gatekeeping of practitioners and furthermore consisted only of those who agreed to participate in the interviews, it is likely that the sample may have been relatively more open to service involvement in their lives than self-neglecters from the general population. That said, not all welcomed outside agencies at the outset of the practice intervention, and their accounts of what practitioners did or did not do to make them feel like willing participants in the process are instructive.

5.2.1 Willingness to engage

When asked about how ready they had been to accept help at the point where social services or other organisations became involved, interviewees' responses spanned the gamut from enthusiasm to extreme reluctance. Five themes were identified in their accounts: 'already wondering', 'seeking help but finding it hard to access', 'no choice in the matter', 'it needs to be the right kind of input' 'the importance of timing'.

Already wondering

It was apparent from some accounts that they had already been wondering whether some form of support might be helpful and what kinds of assistance might be available. A particular incident might have prompted contemplation about the extent of self-neglect and what could be done about it. For instance, one person stated that the impulse to explore possible input had come from television programmes that framed hoarding as a problem that could benefit from professional help:

"I'd seen on the television about the hoarders, you know. I said to the lady who was coming at the time, from the council, I was saying, 'I've heard it's a mental health issue' and she said, 'Well it is, yes. I can put you in touch with somebody if you like' and that's how it started."

Although he was clear that he did not see his own self-neglect as directly comparable to the levels shown by those who appeared in the television programmes, they had nevertheless planted a seed that then led him to take action. For two others, recent shocks had prompted them to think about making greater efforts towards change: for one, it had been the discovery that rats had been inside her house; for the other, it was a council officer suggesting that her home was a fire risk. One woman had been considering taking in lodgers when she lost income, but realised that she couldn't "because the place was in such a state!" This led her to make enquiries at a mental health advocacy charity, which raised the possibility that her hoarding might be due to OCD. Service users with this outlook were predisposed to explore possible sources of intervention, provided that services and workers were ready and able to build on the opportunity presented.

Seeking help but finding it hard to access

Some interviewees reported that they had been keen to access support in dealing with their self-neglect, but that other factors posed obstacles to doing so. Among these factors was often a lack of knowledge of the social care system and what it could offer, often on the part of the people who use services themselves, but also on the part of workers who might be expected to signpost them. In keeping with findings that workers are commonly unclear about how eligibility criteria and effective service interventions relate to self-neglect (Braye *et al*, 2013), one person told how, although a specialist hoarding support service was available in his area, it was only when he had read about another council tenant who had received this input and persistently challenged the tenancy support officer to get similar input for himself, that he was able to access it:

"She complained about me, she said I had to sort it out and as I said I asked for help. She said 'we don't help people sort their own things out' – 'oh yes you flaming well do, missus, because I've got it in here, in Tenants News in black and white, somebody's already

had it.' She said they don't but she went in, that was it.[...] She said there wasn't [a way to access the support] but there was for somebody else. I don't know, somebody in the borough somewhere."

In a different context, the theme of difficulty accessing help was particularly prominent in interviews with those who were living on the street. Many of them forcefully made the point that their self-neglect was an inevitable consequence of the situation in which they found themselves, in large part due to the crisis in available housing options. While all were accessing medical help through health services, they were clear that this did not address the core self-neglect issues, which stemmed from lack of accommodation.

No choice in the matter

Service involvement might be precipitated by a crisis that restricted the service user's alternatives. A case in point was one man's admission to hospital, during which he was told that he could not return to his home, as it was not in a fit state for him to inhabit. When he was about to discharge himself, it was pointed out to him that he was now homeless and had nowhere to go. Some of those who hoarded similarly found themselves in situations where their breach of tenancy conditions left them with limited control over what would happen; for example, despite one person's best efforts to conceal the state of his apartment, when he was unable to provide access for required maintenance work due to the amount of material he had accumulated, he had few realistic options but to cooperate with the council in clearing it. What is interesting about both these cases is that both men referred to a feeling of "relief" and a sense of "peace", respectively, when, despite their earlier attempts to keep services from becoming involved, they were 'caught', and had to engage with interventions. Their accounts of events show how skilled practitioners were able to overcome these less than ideal circumstances and make their experience of input a mostly positive one. However, another individual had on several occasions been admitted as a voluntary or compulsory patient to mental health hospitals, with discharge sometimes linked to either an agreement to enter a hospital prior to living independently or to de-clutter his accommodation. Such conditions had sometimes led to "conflict with staff".

It needs to be the right kind of input

A number of those interviewed did not necessarily object to the principle of receiving help, but were ambivalent about what forms of assistance they perceived to be on offer. One individual, for example, had been referred for a support worker to help reduce her hoarding, but said that she did "not like the thought of someone going through her stuff" – it was important to her that any assistance offered should not be intrusive. Another, who also hoarded, clearly and simply expressed this theme by saying that help provided had to be "how I want it done"; she felt strongly that the best starting point for practitioners is to listen to the person, who knows what is needed and where to start. She also raised the issue of cost; she had significant debts as the result of shopping trips that had contributed to her hoarding, and was resentful of being asked to pay for help. Someone else, meanwhile, having said that she had not benefited from cognitive behavioural therapy (CBT), complained that she had not been offered "psychotherapy", which she distinguished from CBT – she felt that it was important that authorities "make sure that we get the therapies that we need, be that counselling or psychotherapy or whatever."

The issue here was one of choice and the extent to which the service user's judgements on the most appropriate form of help were respected. Not all interviewees reported having had specific concerns that input should be 'of the right kind' when services first became involved; however, if the support given was not sensitive and appropriate, this quickly became an issue.

The importance of timing

Whether or not there was a crisis point that restricted interviewees' choice and control over what happened in their lives, many underlined that the timing had to be right for them to respond positively to service involvement. One individual, looking back over years of self-neglect with its roots in his adolescence, felt that he only became ready to learn about his psychological "triggers" in his mid-twenties, because previously his priority had been looking after his younger siblings and not himself. In order to keep the family together, he tried to hide his own problems from others. Another traced the deterioration in his care of self and environment back about 10–12 years, but when asked if anything might have been offered at the time that could have made a difference, replied "If there was I wouldn't have accepted it probably, it wouldn't have been appreciated." For him, the experience of the intervening years and seeing the television programmes about hoarding – one might also speculate that recent conflicts with his neighbour, who was threatening to have him evicted for breach of tenancy conditions, may have played a part – were necessary steps in reaching a position where he was willing to accept support. Early intervention, before self-neglecting behaviour becomes entrenched, is recommended in the research literature (Day and Leahy-Warren, 2008; Braye *et al*, 2011c), but these comments highlight how hard this might be to achieve.

The question of capacity was little discussed in these interviews in explicit terms. Given that only those who demonstrably had capacity to consent to be interviewed were included in the study, this is unsurprising; practitioners had needed to respect their autonomy and convince them of the value of any input that they offered. However, it was clear that capacity was an issue with which one of the family carers interviewed was wrestling:

"Early on she was diagnosed as having Diogenes Syndrome, which is a mental condition. Reading a bit around it, it means that people don't have a choice, yet on the other hand, authorities and whoever were saying that she does have a choice, so as someone in her family seeing her living in this appalling condition, I felt as though we were falling between two stools, like she's got a choice to live like that, but she has got this mental condition so she hasn't got the mental capacity, and for me I was having to square a circle, and I still haven't quite got where we can go on that."

This study has shown that capacity is a complex question even for professionals, so it is understandable that this carer, seeing her mother-in-law in squalor and self-neglect, questioned how far her living standards needed to deteriorate before action could be taken.

5.2.2 Practitioner approaches to engagement

Just as the interviewees' outlooks on the idea of support or other input varied, practitioners were reported as having responded to their concerns differently. Interviewees were specifically asked how they had felt about service involvement at

the outset; their answers showed what, for them, counted as positive approaches to working with self-neglect. The practical form that intervention took was important, but so, too, were the impressions conveyed by practitioners. Indeed, the significance in their accounts of how practitioners related to them is impossible to ignore, constituting the most remarked-on aspect of the input they received. Self-neglect is notable for presenting significant challenges for practitioners in building relationships with people who use services (Day *et al*, 2012), but numerous examples emerged from the interviews where the challenge had been met and overcome, even under unpropitious circumstances.

The comments by interviewees about how different practitioners or workers had engaged and interacted with them are grouped under six overarching themes: 'directiveness', 'hands-on vs hands-off', 'person-centredness', 'going the extra mile', 'reliability' and 'normalisation vs over-reaction'.

Directiveness

By the time services had become involved, most interviewees had recognised that they were in situations of stasis or even of deterioration with regard to self-neglect. Yet practitioner approaches that felt overly directive were nonetheless deeply unwelcome. The interviewees spoke of tenancy support officers, council officials, social workers, support workers, environmental health workers and therapists who had, in their eyes, been unhelpful. They used words like "nagging", "bossing", "grating" and "pushy" in speaking of this kind of approach; one person mentioned a tenancy support officer who, in his view, began "criticising, oh, as soon as she walked in and I thought she don't want to start this criticising, this is not helping me." Not only was it disaffecting and hence made a positive working relationship less likely, it also sometimes provoked resistance to otherwise constructive suggestions for how to move forward:

"With me if you're too bossy, I will put my feet down and go like a stubborn mule; I will just sit and just fester."

"Recognising self-neglect earlier I think is important, once it's recognised earlier then like I say, the idea is not to get too pushy about it, people start getting panicky then, you know? 'You're interfering in my life,' that kinda thing."

On the other hand, interviewees attested that it was entirely possible for practitioners to get them to make significant progress by being less overtly directive. They preferred to be "encouraged" to do things rather than "pushed", and valued it when, for example, workers knew "when to back off a little bit" or when "they don't force nothing on you". Occasionally the interviewees in this sample found themselves in situations where they objectively had limited choices open to them, but even so, they found that practitioners might handle this sensitively. One man, who was not permitted to return to his home from hospital, said of how his social worker handled the situation: "He's down to earth, he doesn't beat around the bush. If there is something wrong he will tell you. If he thinks you need to get this sorted, he will tell you." He appreciated the candour, as well as that the social worker had managed to avoid making him feel that he was being railroaded for no good reason. Less positively, another individual was clear that "it does not work forcing things on people; it made me worse." Clearing his house of his collections of magazines and tapes, sometimes because of fire risk, had not helped because of what he described

as his obsessional need to collect. These interventions had not helped him to relate to people or overcome the impact of his childhood.

Vignette: Jim

Here practitioners needed to find the right balance, offering services but not being too forceful; it was important to recognise the impact of the past, and the power of emotions, while also setting a direction for the future, however small the steps and however tough the challenge of finding motivation.

“I’ve been homeless for three years, and I went on the road not having any particular direction. With certain towns in Britain, there’s no facilities for homeless people so personal hygiene gets difficult. You feel like you’re taking up a public space and a slight amount of embarrassment, so you tend to like, you let yourself go a bit. I became homeless after my marriage broke up – 15 years, so that gets to you to start with, the guilt and the sense of loss. Then you find yourself on the streets and you have to deal with the loneliness and the way some people treat you.

“So you do tend to self-neglect yourself in that area, because you’ve got all these feelings and all these emotions, the last thing on your mind is getting in the shower or doing a bit of art or painting a picture, so I have to motivate myself, force myself to do these things, like when I get up in the mornings, getting off a bench in the morning, you don’t want to get out of your sleeping bag, but you can’t afford to let yourself slide too low. Because otherwise, I wouldn’t be sitting talking to you, I’d be sitting talking to the mental health team and I’ve been close to it a couple of times down the road.

“So, yes, self-neglect I think, a lot of it is mind-set. This place for instance gave me a little bit of hope when I walked in here. ‘I can relax,’ people show me the way to go rather than me think ‘I know best, I can do it my way.’ Just accept the services and accept what they’ve got. Accept their help, it takes time and I’ve learned that now, have a bit of patience and every day’s different, you’re coming in and every day’s a different day. You don’t know what’s around the corner. With people who are self-neglecting, I would say offer them the services, don’t be too forceful with the services because people get cagey, they start thinking ‘What do they want with me?’ and they get a bit wary of being approached by authority.”

Hands-on vs hands-off

Although the manner in which support was offered may have been as important as the support itself, the interviewees very much appreciated practical assistance. Some of those who hoarded, speaking of how their situations had first come to the attention of the council or housing support, noted that while they may have been encouraged to clear their accommodation, they were rarely offered practical assistance at first. One person felt that

“... tenancy support started coming up but they weren’t helping, they were just leaving it for me to do. Whereas when [the specialist hoarding support worker] and his colleagues came, they were sort of hands on, ‘Bumph! We’ve got to do this’ and ‘Uh?!’ When you first came the first morning it’s like, ‘Well, shall we start cleaning up now?’”

He was taken aback at the shift from 'hands-off' instructions and encouragement to 'hands-on' work that went beyond discussion and straight into action, but impressed at the rapid progress made. Another, now that he had accessed the same specialist support, similarly noted the contrast with the council worker who had previously supported him:

"She came for about six weeks but decided she 'wasn't qualified' to watch me sorting out my things and cleaning my kitchen and doing whatever[...]. She 'wasn't qualified' to do that, to watch me! Anybody can do that!"

She "passed the buck", as he put it, and he now had a hoarding support worker. Now that this dedicated assistance was in place for four hours a week: "That's it. We're doing it". One woman, meanwhile, complained that a support worker had "just moved stuff around to make the place look tidier but he didn't really achieve anything in the long run"; it was important to her that help provided should not just be superficial. As well as practical help with clearing, other assistance could also be thought of as 'hands-on'; one person's social worker had been encouraging him to go to a social club to reduce his isolation and self-neglect, but despite initially agreeing, he had

"... kept saying I wasn't well, I wasn't well and that. And then yesterday, [he] rang me and he said, 'they're coming to pick you up in about half an hour' and I said 'I'm not even ready.' He said 'don't worry about it,' and said 'just go there and see what it's like,' so I did. And I liked it so.... I'm gonna go back again tomorrow."

The significant factor here was the support worker's willingness not to stop at giving advice or making suggestions, but to act to ensure that progress was made.

Person-centredness

One individual gave his support workers credit for having "got it into my head that I am important, that I am on this earth for a reason", through taking the time to talk. This had helped him to manage, if perhaps not to overcome, quite severe depression and feelings of worthlessness. Other interviewees similarly spoke of how individual practitioners had focused on them as people, and how this had been hugely important in providing a firm foundation from which to move forward. One man mentioned a student occupational therapist who "gave me some belief: 'you are clever, you can do this if you want to, you've got a lot to offer'." For another, the workers supporting him and others in his situation were "very helpful and when you do try to get help, [they] make an effort and the outreach workers, they also make an effort, they're genuine, they're not jobsworths."

To feel that practitioners cared was of central importance to the interviewees. However, some mentioned more negative experiences. One person complained about her first social worker, who she said had "sat in a chair with her legs up and said what do I want, and a blank piece of paper, and that's just not right because it misses out huge areas of your life." Her critique was echoed by another, who believed her current social worker "does not care about me as a human being." While she said she had encountered social workers who did seem to care about the individual, others seemed only interested in completing processes such as reviews. Like others, she was unhappy with forms and recording, objecting that the care workers "only record what they did; they do not write about how I am." Another

person also recounted how, on the first day of the clearance of his flat, the social worker had been too driven by the assessment process rather than the person in front of him:

“The social worker said, ‘I can’t see your toilet, I can’t see your toilet’, I said ‘yes’, he said ‘I can’t see your bed’, you see the social worker was doing his duty, the social worker from his point of view was to see that I’d got access to a toilet but at that stage in the procedure, even if there’d been no toilet and there’d been no bed, that’s further down the line. But he was doing things by the book, which was quite unnecessary and had I been a different person, [... I] would be in terror.”

The importance of going at this person’s pace rather than that of the practitioner is underlined in this quote. This focus on the person with whom practitioners are working also appeared in another person’s emphasis on “listening to” people who use services and another’s insistence that workers should “find out a little bit about the person you’re going to go and meet.”

Going the extra mile

One individual contrasted two different support workers she had had. One

“... sees the needs. I don’t have to tell him, ‘[...] could you bring me stuff in [to hospital]?’ I don’t have to tell him, he just comes with it, [that time] he came with three bottles of pop and a couple of ready-made salads. I paid him for them; I thought they got all that paid but they don’t.[...] But if that was the other one, he’d be saying, ‘Oh, just call a cab and go home on your own,’ and then I’d have to get out the other end and make my own dinner. But the other guy realised I was weak and I needed a little bit of pampering[...]. It didn’t matter about the rules, he goes that extra mile.”

Gestures like this counted for a lot. One man, when asked about how his hoarding support worker had worked with him, responded, “He has been human, that’s the word I can use. He has been human.” One way in which he had shown this was to ensure the man got an invite to a Christmas dinner he had voluntarily organised for the service users: “I thought, ‘You know what? That’s what it should be like. These people do care’.” Another individual, who was frustrated at being unable to get accommodation and get off the street before the winter set in, nevertheless gave the centre staff full credit for their efforts on his behalf: “I think the staff here are amazing, brilliant, they will bend over backwards to help you.” People who self-neglect, who frequently may not meet eligibility criteria or may find it difficult to engage with the support on offer, still take note when particular workers or practitioners are able to make the extra effort.

Reliability

A number of interviewees highlighted reliability as a key element in enabling them to trust and work with practitioners. For some, previous experiences of loss or being let down meant that they were particularly sensitive to appointments being kept punctually, to being informed when practitioners were going to be on leave and therefore unavailable, and to continuity of practitioner. One interviewee, while

admitting that he was “not the most reliable person” himself, set store by practitioners’ punctuality, and spoke about how short-notice cancellation of appointments would get him down. Many interviewees emphasised the importance of reliability. For instance, one person highlighted that this was not just about being on time, but about having “carers who care and have the time to get on top of things and then keep on top of things.” Attending appointments on time and consistently was not just about reliability, but about respect, creating space for quality input and showing commitment to the service user as a person.

Normalisation vs over-reaction

The interviewees valued calm and understanding reactions to their self-neglect. As we have seen, some – although by no means all – had lived with shame and fear over how their self-neglect would be seen by the outside world, and given this background, were sensitive to how workers responded to them. One man, whose terror at the prospect of being found out has been described above, found himself immensely relieved and grateful that council workers were unperturbed when he finally admitted the extent of his hoarding:

“They said ‘ah well, we’ll have to work something out,’ and they were so kind, even now three years later, they were so kind. I thought they were going to say, ‘you silly old bastard.’ I thought they were going to jump on me.[...] They all said, ‘we’re not here to condemn you, we’re here to help you’ and I couldn’t believe it. I thought I was going to get an enormous bollocking.”

They emphasised to him that “we find one of these in every estate, sometimes one in every block”, helping him to understand that hoarding was not so unusual. This compassionate approach did much to facilitate constructive intervention with him, although he was also able to identify moments later in the process when practitioners were less thoughtful:

“One [worker] I had to admonish because people like me, we’re not proud of the state [of our living space] and even after the clearance, he came in and said, ‘you’ve got a lot of stuff’ and of course there was a lot of, the stress levels were very high.”

Amidst the stress of clearing years’ worth of accumulated material, small remarks like this were experienced as negative and unhelpful. Another person, meanwhile, after telling her social worker that she had heard a mouse in her house, felt that the ensuing environmental health enforcement response had been disproportionate:

“She made me pay to have the council people come in, the council pest control officers come in and they brought in their poison.[...] So all that money wasted for a silly little mouse that I would have got myself anyway with my own poison. She’s putting a lot of pressure on me, she knows I’ve got a mental illness and the root cause of hoardism is anxiety and ... she just makes mine worse.”

Whether or not the response was reasonable, this person certainly experienced it as stressful and not fully justified. For her and for others, a calm and considerate response to the consequences of self-neglect went far in establishing a positive working relationship.

5.2.3 Implications

The interviewees recounted how, when they came into contact with services, they started out from a variety of situations and dispositions, suggesting that practitioners need to be able to show considerable flexibility in response to what they see as their needs at that particular moment. Some were clear that there were times when they were not open to help, but that they subsequently became so; this recalls the points made by some managers and practitioners about the importance of persistence and not giving up on people too readily. Honesty was appreciated, but had to be tempered with an understanding of the perspective of those who self-neglected; when characterised by excessive directiveness, it was no longer considered helpful. Also greatly valued was a willingness to actually get involved in what needed to be done, instead of advising from the side-lines. Service users could experience implied or overt judgements by practitioners as oppressive, so workers should give thought to how they appear to respond to the situation before them.

5.3 Interventions and outcomes from the perspectives of people who use services

A range of interventions was used to attempt to address the different forms of self-neglect described by the respondents to these interviews. Some of these were felt by people who use services to have led to improvements in their lives, while a number were reported only to have stopped the situation from getting worse, if they had even achieved that much. Not surprisingly, given how diverse the situations of these people were and the lack of any standard measures to assess severity or outcomes, no 'magic bullet' emerges from the accounts as consistently indicated for intervening with self-neglect. However, there are hints at what the interviewees found to be effective, disappointing or frustrating, which hold lessons for practitioners and for services.

5.3.1 Specific interventions

Support with clearing

Six interviewees spoke about support they had received to make progress in clearing hoarded materials from their accommodation. For three of them, this came from a contracted social enterprise that specialised in hoarding support. All three spoke highly of the input, which ranged from between 2 and 4 hours per week. One said that his support worker had

“... moved stuff around for me and chucked most of the clutter away and encouraged me to throw other things away which I didn't really want to throw, but in the big way of looking at things it's best, I suppose.”

This support had helped to “kick start” him; even the suggestion of using a bin rather than throwing rubbish on the floor had made a big difference. Another did not identify as a ‘hoarder’ but as a “gross collector”; nonetheless, he wanted “to get back to a way of life that I'm comfortable” by reducing the clutter in his flat. For him, the support worker was “like having, I don't know, a friend who's come along [...] who says ‘Alright, how are you doing, mate? If you need any help doing that,’ and that's what I get from [him].” Although another man laughingly commented that his support worker “moves things around and I don't know where they are then”; he was pleased that his support had increased from 1 hour to 4 hours a week, and felt that together

they had been able to make good progress with parts of his apartment, whereas on his own it had been very difficult to de-clutter or to clean.

The support that another individual had had to clear his apartment came about differently; when council maintenance men needed access to his property, it had come to light that he had accumulated around 20 tonnes of material there. Although he felt that aspects of the clearance could have been handled with more sensitivity, overall the outcome left him feeling “at peace”. Someone else, on the other hand, felt that the input she had had from a support worker had achieved little of substance, reorganising to make her house look neater but not actually clearing material. Two volunteers had helped her in their spare time, and she reported that this had achieved more than her official support worker: “There was very little skill in it, just a lot of patience and understanding.” The clearing and cleaning of another’s house had been largely organised by her son, although it was closely coordinated with her social worker and made use of a specialist agency. Care was taken not to throw away anything that might have meaning to her, although this still left enormous quantities of accumulated rubbish to discard.

It is hard to judge how sustainable these interventions might be in themselves. Two service users had care packages put in following the clean-up, with regular visits to help maintain tidiness in their accommodation. As a result, his flat and her house had been kept clear. These were the two interventions that involved rapid and thorough clearing, resulting in both cases from crisis points, rather than slow, carefully agreed clearance work (although one of them had received sustained input laying the groundwork in the time leading up to the crisis). It seemed that the crises had led them to accept intervention, but drastic action of this kind may not necessarily always work more effectively than slower, more participatory approaches (Lauder *et al*, 2005; Chapin *et al*, 2010). With regard to the evidence from such slower approaches, the clearing of one person’s house so far appeared not to have achieved lasting success, while the other work on clearing was ongoing and its sustainability therefore a question for the future. Periodic clearances of his accommodation had not helped one individual because he derived psychological benefit from his possessions. What he felt he needed was help “to get used to being around people.”

Others felt that support work might be useful for them in dealing with their hoarding, but had not been able to access this to date, or thought that other members of the family would not accept the presence of a support worker, and were not comfortable about the idea of someone going through their possessions.

Mental health services

Seven interviewees reported that they were or had been in contact with specialist mental health services. Four were hoarders, and were being or had been prescribed psychotropic medication. While the first two felt that the medication kept the voices they heard, which told them to keep everything, under control to some extent, it did little more to resolve their situations. Another made little comment about her medication, an anti-depressant, other than that it had led to weight gain. The other three neglected their self-care. Among them, one individual had a diagnosis of bipolar disorder, but remained suspicious of the lithium he had been prescribed. He was distrustful of the pharmaceutical companies that manufactured it, and indeed of the professionals who had been involved with him:

“Medication comes from drugs multi-nationals which are not necessarily there to help, they’re there to help their shareholders and profit which doesn’t necessarily put duty of care or the health of the patient ... so not interested, I mean they put lithium in me, lithium[...]. I know I need support of professionals to help me self-right but I don’t trust them, I don’t trust any of them and it’s a very tricky place to be.”

Another individual, who had only just been diagnosed with ADHD, and a further person, who had long-standing mental health issues since a breakdown had led her to drop out of university, had little to say on the matter of medication. Another had not found psychiatric or psychological intervention ultimately helpful because he still had major difficulties relating to people, and it was to this that he attributed his collecting of magazines and video tapes, even though it was stressful having to work out what to buy and what to do without.

One interviewee had been through alcohol misuse rehabilitation and had learned some CBT techniques there, with which he attempted to develop routines for himself: “brainwashing, but kept me safe, kept me away from [...] the pub.” Another individual spoke about the importance of CBT generally, and specifically the significance of routines, in enabling her to go outside, to be able to wash herself and achieve a level of self-care. She had previously had a total of 4½ years of psychoanalysis, which had helped with her self-neglect, but she relapsed when she became mentally unwell. Although she felt that CBT was “perfect for working with specific things such as washing your hair and hovering, doing the washing up, dusting, all that kind of thing” – the day-to-day struggles of self-neglect – she still said that if she could afford it, she would continue with psychoanalysis today. The other person said of her CBT that it had been “the same old exercise”, without “getting too far”, and had eventually given up on it. She argued that she should be given access to more psychodynamic therapies, to “talk about why you hoard in the first place”, but said she had been told she was not suitable for this – a judgement with which she vehemently disagreed.

Four others mentioned counselling or psychology input without specifying a particular model of therapy, or, for the most part, providing many details. Among this group, one person spoke about having gained an awareness of the ‘triggers’ for his self-neglect, which is language that might suggest a CBT model, and highlighted how helpful he had found this formulation to self-understanding and keeping control. However, there was little evidence that psychological input for two others had done much to keep their accumulative tendencies under control, and the fourth did not attribute success in keeping his flat clear to psychology.

Taken as a whole, mental health service involvement with this set of people who use services seemed to them to have achieved at best maintenance or minor improvements, rather than outright solutions to their problems of self-neglect. CBT had been useful in some cases for work targeted on specific challenges, and for one person in gaining understanding of his cognitive patterns, but others felt that it had not addressed the deeper causes of their self-neglect, and thus ultimately had not made enough of a difference.

Linking with other people who use services

Two of the interviewees put a lot of emphasis on the benefits that could be gained from others who themselves had self-neglected in the past and who could pass on

lessons about how to overcome the challenges. For both, knowing that support was available from someone who had coped with similar issues was significant. One individual, who had struggled with addiction and homelessness, spoke highly of a worker who had “come through it”. The comparison he made was: “If you want to be a football manager, you have to be able to kick a ball”, and he commented that “people that have come clean, they know what it’s like”. Another argued that mental health professionals “can only make an assessment from an outside perspective” and felt that he benefited more from input from “people who have had breakdowns in the past, who have identified what is good for them, rather than people that have learned from books.” In their view, knowing that the person working with them had faced and dealt with self-neglect both provided an example showing what was possible and meant that they would be treated with greater empathy.

Other interviewees spoke of the benefits that could come from peer support. Unlike the examples given above, they spoke of peers who continued to deal with the challenges of self-neglect, rather than those who spoke from a position of having learned to overcome them. Four people attended a hoarding support group. Two others were involved with a similar group, but as it had just been launched it was difficult for them to comment on its level of success. The value attributed to the established group by the four service users who attended it seemed to lie more in the social support it provided than in therapeutic success in helping to bring their hoarding tendencies under control. As one put it,

“... it lets you know that you’re not the only one trying to get help [...] and apart from the fact that it might not actually help your hoarding as such, it kind of gives you a bit of peace of mind that you’re not a complete out-of-space weirdo and that it is a lot more common than people realise.”

The others highlighted that such groups helped them feel that they were not alone. Given the shame and self-doubt that some of the interviewees felt in connection with their hoarding, and the potential for social isolation that it could cause, this may be an important function, and was certainly valued by them.

Other interviewees spoke of the value of different group settings, which were not necessarily focused around a specific issue in the same way as the hoarding groups. Groups and activities for older people had been helpful in mitigating the effects of self-neglect for two interviewees: one person attended a day centre and liked the company of other attendees, while another, although initially sceptical, reported that he enjoyed the “social club” that his social worker had “pushed” him to attend. Three people, all of whom were homeless, mentioned the value of the day centre they attended as a space to meet and, to some extent, relax in the company of others, which could be difficult on the streets. Although some noted that groups could be negative if members started to weigh each other down with their problems, they felt that they also had the potential to provide positive input that could help them to deal with self-neglect.

Engaging in meaningful activity

A particular issue identified in relation to self-neglect was the loss of purpose and meaning that it implied. For some, joining in groups was a way of becoming involved in socially meaningful relationships and activities. The interviewees explicitly raised becoming able to feel that they were making a contribution, or were active in

something worthwhile, as an important intervention with self-neglect. For one person, this had been selling the *Big Issue*, which had represented “a bit of dignity”; for another it was the aspiration to get on to an educational course; someone else hoped to be able to recover enough to be able to provide to others the support that he felt was so beneficial to him. Another valued the opportunities provided by the day centre to cook for its users and to participate in art projects; yet another thought he might be able to run art projects and creative activities in the future, as part of the hoarders group or through MIND. When one individual was asked what his advice – based on his experience – was for workers supporting people with self-neglect, he answered, “Look out for interests and activities in which this person could get involved.” One person found that having a focus helped, in a day centre and in a group for people who use services. Although some of the activities mentioned were aspirations or intentions rather than things that the interviewees were doing at the time, they still provided a goal to aim for, and in this way worked to counteract the demotivation that self-neglect often provoked.

Relationship building

As shown earlier, relationships were often significant among the reasons why the interviewees self-neglected in the first place, and it is clear that practitioners sometimes worked at building relationships in order to engage people who self-neglect. Some interviewees further highlighted the significance that positive relationships could have in contributing to recovery from self-neglect. Two people both spoke of the boost they had received when individuals had seen potential in them that they felt was not apparent to anyone at the time. One of them spoke of someone who had “seen more than what I am, in the sense that you see me like this [ie, self-neglecting and homeless]” and how much that had meant:

“I think the only thing that will help that is concern, another human being connecting with you that’s got a little bit more strength than you, that pulls you through those forms of depression, that’s what keeps you alive.”

He singled out paramedics for praise as “medically qualified but also emotionally qualified”, because in his view they were so often able to make that connection quickly with people in despair.

While the clearing of another’s house and the resolution of her hoarding had been precipitated by a plumbing crisis, the groundwork for her acceptance of respite care had been laid by the patient involvement of her social worker. He had taken the time for repeated visits over a period of seven months, ensuring that each time they did something that she enjoyed. Someone else contrasted this kind of professional relationship, involving genuine listening and help, with what could feel like more superficial support from workers:

“Give them all the help they need – don’t just sit there and say you’ll do this, you’ll do that, then it never gets done. Because that’s what you hear from some of them, ‘We’ll do this, we’ll do that,’ then there’s months down the line, just something still hasn’t been done and they’re still in the same situation.”

To feel able to rely on workers who cared about them as people was valuable to the interviewees and could help to lay a tentative foundation for recovery, just as it worked to help them engage initially.

Vignette: Max

Here the practitioner and the service user take time to build a strong relationship that is based on respect, honesty and trust. The practitioner seeks to understand the meaning of the self-neglect; he recognises the individual's own motivation and strength, and works at his pace; the individual finds the strength to give up things of great personal value. Their relationship is at the heart of the intervention.

Max, in his early eighties, lives in an upper-floor council flat, and had hoarded over many years: his own possessions, items inherited from his family home, and materials collected from skips and building sites in case they came in useful. The material was piled from floor to ceiling in every room, and Max lived in a burrow tunnelled through the middle, with no lighting or heating, apart from a gas stove. Finally, after years of hiding in privacy, Max had realised that work being carried out on the building would lead to his living conditions being discovered. Max himself recounted how hard it had been for him to invite access to his home, how ashamed and scared he was, and how important his hoard was to him, having learned as a child in the war never to waste anything.

Through working closely together, Max, his support worker and experienced contractors have been able to gradually remove from his flat a very large volume of hoarded material and bring improvements to his home environment. It has taken time and patience, courage and faith, and a strong relationship based on trust. The worker has not judged Max, and has worked at his pace, positively affirming his progress. Both Max and his support worker acknowledge his low self-esteem, and have connected with his doctor and mental health services. The worker has recognised the need to replace what Max is giving up, and has encouraged activities that reflect his interests. Max has valued the worker's honesty, kindness and sensitivity, his ability to listen, and the respect and reciprocity within their relationship.

While in most interviews, relationships with practitioners – or, occasionally, peer input from those who had faced similar problems – had been the key to improvement in self-neglect, in one case a different kind of relationship made a significant difference. Having struggled for years with self-neglect of his emotional wellbeing and health, one person spoke of how becoming a parent had been the “trigger for wanting to change” that moved him to improve his self-care. Two people had given credit to their partners for mitigating their tendencies to accumulation, although the former acknowledged that this had, at times, put significant strain on their relationship. Only two carers were interviewed for this study, so we have little data on family members' perspectives on self-neglect and on what support was needed or helpful for them. The value of this source of support for self-neglecting individuals, where available, should not be underestimated; however, both existing research (Wilbram *et al*, 2008; Sampson, 2012) and the accounts of these interviewees suggest that they, too, may need support in coping with the demands of this role.

Self-reliance

While the value of relationships, peer support and practitioner input came through in many interviews, six interviewees also placed considerable emphasis on their own individual responsibility and achievement for overcoming, at least partially, the factors contributing to their self-neglect. All six were homeless, and the importance

they placed on self-reliance stemmed in part from their success in meeting the challenges presented by living on the streets. Some of them spoke of their disappointment and anger that, despite health problems, they were not rated as 'vulnerable' enough to qualify for housing. While they felt that they were self-neglecting, and in some cases this may have contributed to them becoming homeless in the first place, they also raised the question of the extent to which their self-neglect was the consequence of neglect by others, primarily the council. Faced with what they experienced as indifference, they were thrown back on their own inner resources.

One of them described how he wrestled between demoralisation that could lead him to neglect his self-care and the urge not to give in to his situation by letting his appearance deteriorate. He commented,

"Now this is the way I see it, I might be totally wrong, you've got to want it. If you know you smell and you're happy with it, then you're happy with your self-neglect. If you're not happy with it, then you make sure you find somewhere and get a wash."

For him, the ability to cope with and resist self-neglect was as much about personality and determination as it was about support and input from others. Similar sentiments were expressed by others who had struggled with addictions, when asked what had helped with self-neglect:

"Me. Just me. I had to get on with life, so to try and pick myself up.[...] All on my own. No help from anyone because I didn't like to discuss it with anybody."

"It's a matter of self-control, because I've worn the t-shirt, I've done it, I've been drunk and I've been a bloody idiot as well.[...] Me. At some point, this might be a generalisation but at some point I took a good long hard look at myself and was disappointed. Got to regain control of myself. So basically that's what I've done, maintained control.[...] I don't want to say it's willpower as such, it's a matter of you've got to, mmmm, it's like at some point there's a gun towards your head, you've got to do this, me pointing a gun at my own head like, 'you've got to do this otherwise you're gone', like, you've had it, end of story."

"Making my mind up. It's up to me."

Many of the interviewees in this study made it clear that outside support had been hugely important to them, and they, too, valued it where they had found that it was made available. But the perspectives of these six are a reminder not to ignore the inner strengths that individuals may try to bring to bear on self-neglect, although this should not mean ignoring the need for service input where it clearly exists.

Accessing resources and advocacy

Practical help was a form of assistance that many valued highly. Help with paperwork and practicalities was invaluable to those who, because of limited attention spans or difficulties with literacy, found themselves unable to identify or apply for the benefits to which they might have been entitled. Even where there were no obstacles of this kind, they were sometimes simply unaware of what they should be receiving; for instance, one person's social worker discovered that he should

have been getting disability benefit for the previous three years but had not realised this. When there is no service input to provide information, or when services fail to do so, the lack of self-care characteristic of self-neglect made it less likely that people would look into possible benefits for themselves.

Other interviewees benefited from assistance with budgeting and financial management; in one case this included introduction to online banking for someone who said he had never previously used a computer, which proved constructive in facilitating greater self-reliance in handling his finances, while some hoarders also received input on their budgeting and purchases. It was not just information that was welcomed; three all praised day centre workers for their persistent advocacy in trying to secure housing for them.

“They’ve done everything, they’ve called all the services, they’ve badgered, harassed, harangued, whatever word you want to put it, they have beat the hell out of people to try and get me somewhere to stay. I’ve had one of my key workers come down to the council with me and argue with them, these guys do go out of their way to do everything they can, there’s no ifs and buts on that, I’d stand by these guys 24/7, no problem.”

For all that their efforts had so far been unsuccessful, the commitment shown by practitioners had not gone unnoticed.

Care packages

Six of the interviewees now received regular visits to provide personal or domestic care. While these were generally now welcomed, sometimes despite initial reluctance, problems remained in one or two cases. One person complained that the cleaners were refusing to clean when they came, although they claimed that she was turning them away. Another’s main complaint about her care visits was that they did not last long enough, but she also had reservations about not being able to find things after they had been (which resulted in her buying extra items which she would not otherwise have needed, thus – she felt – adding to her hoarding problems). The other interviewees were positive about their care input, perhaps reflecting the attention that their social workers described paying to ensure that the agencies understood the nature of their particular manifestations of self-neglect and how best to work with them.

Interestingly, only one interviewee said that she had received a personal budget. She felt that this was an improvement on the previous system as it put money directly into the hands of people who use services without it being diverted to other budgets, but criticised one of the social workers she had had for not doing enough to help her spend it: “He himself has not done much to contribute, to spending my budget or getting me help to spend my budget or getting me services.” With the help of a new social worker, she had been able to use it more effectively to provide herself with constructive activities. One other interviewee discussed personalisation, mentioning that she would like a direct payment in the future. At present, however, she was “finding everything overpowering”, and thought that perhaps social services could do the paperwork for her if she did access a direct payment.

Re-housing

Housing issues were significant in the accounts of several of the interviewees. Most obviously, they were of overwhelming importance to those who were homeless. While they acknowledged that self-neglect was an issue for them, for most it was less important than addressing the immediate problem of accommodation (although for some, the two issues intertwined). For example, one person was receiving considerable mental health input for bipolar disorder (not all of which he found helpful), but set out his priorities in stark terms:

“Someone said to me, ‘what is it you need?’ and at the time I found that a very insulting question because to me the answer seemed pretty simple. I had no income, I had nowhere to live, so the first two things I need is money and somewhere to live. You don’t need to ask someone who’s homeless, do you know what I mean?”

Re-housing had also become an issue for others. One individual’s house had become so unhealthy that he had not been allowed to return to it on discharge from hospital. He spoke of relief that mingled with his concern about where he was to go, and how he was “fed up with being cold as I had no heating, fed up with not being able to walk into the bathroom because of the mould, fed up with living in one room because of the mice.” Although he had resigned himself to his circumstances and said that he would not have taken action himself, being re-housed had led to enormous improvements in his quality of life. One person had benefited from moving into a supported mental health block. Another was awaiting an impending move that was less positive; following the death of her mother, she was now under-occupying her flat and would have to relocate. In direct contrast to the hoarders and collectors interviewed, most of her possessions seemed to mean little to her:

“I’m not taking my furniture. I can’t take my belongings. I didn’t bring them when I moved here either; there was no room for them here then. You learn not to get attached to stuff when you have to keep leaving things behind.”

She said that she wanted to “be local” as it was “less scary”, although she said she was “a loner; I don’t need friends.” Her situation is a reminder that self-neglect is not always about hoarding and accumulation – for her, a sense of instability and marginalisation seemed to mean that she resisted becoming attached to possessions or people.

Temporary residential care had been used with two interviewees to manage crises and to make intervention possible. This had been necessary to make time for a deep clean and, in one case, de-clutter that would ultimately lead to the return of the service users to their homes with a care package to maintain the improvements. Although her social worker had had to argue hard for this to be funded, it had had a positive effect, not just in the practical sense of enabling the clearing and renovation of her house, but also in reminding her that another, more comfortable, lifestyle was possible. In this way, she became more willing to engage with the care package that would follow.

Involvement from environmental health and other agencies

Eviction had been a consideration for some of the interviewees, whether threatened by others, such as neighbours or the council, or in their own mind. However, encounters or discussions with enforcement agencies such as environmental health were mentioned only once. One interviewee reported that “she’s putting a lot of pressure on me, she knows I’ve got a mental illness and the root cause of hoardism is anxiety and ... she just makes mine worse.” She felt that the enforcement officer continually over-reacted (eg, by instructing her to throw out all her linen because there had been signs of a mouse in her linen cupboard, rather than letting her wash it at high temperatures), gave her ultimatums which she found very stressful and showed little sympathy for her mental health issues. “If she left me alone, I’d plod on and I’d get it done but she comes round ruling the roost, giving me ultimatums and blah blah blah.”

Although no other accounts of environmental health were gathered from these interviewees, this description is not dissimilar from some presented earlier about the ‘directiveness’ of encounters with tenancy support officers (TSOs). One person, for example, had perceived his TSO as ready to complain to him but not to offer any assistance or suggestions to help in improving matters. Another recounted how a district nurse had suggested that hoarded possessions might be a fire hazard, a view towards which he reacted negatively for similar reasons:

“I think it’s a little bit unfair because in saying that something is a fire hazard, you’re putting an immense amount of pressure on somebody to deal with their stuff, more pressure than it might be reasonable to place on them because any mention of fire is a massive threat and ... but just how much of a fire hazard it is, I don’t know. There is risk in life, we can’t get away from risk and anyone who smokes [...] is probably risking a fire much more than somebody who [...] lives with a lot of papers but who doesn’t smoke.”

It is clear that these interviewees experienced such communications as oppressive, and seemed to feel that they do little to change their behaviour.

Better information

Some interviewees, when asked what could be changed for the better, suggested improved publicity and information about the services available. One person had lost his job and become homeless, partly as a result of mental health issues, but had been unaware of the help that might have been available until he was finally signposted to social services by his GP. So, when asked what could be improved, he responded:

“... the only advice is I was struggling to get this but it took me a while to get to know, there probably have to be more advertisement for some people so that they know where to go, me I didn’t know where to go.[...] Probably a sticker there, ‘call this number’, something like that, more than me struggling for two months or three months – just to look at places where they are, I’ve been here almost 12 years and I didn’t know they were there.”

Others, while aware that there were services that could offer support, felt that it would be helpful to give them greater positive publicity, as they had felt an initial

reluctance to let social services become involved. A family carer, for example, pointed out that there might be a need to promote what social services can do in situations of self-neglect, as was done for adult safeguarding:

“So maybe there’s a reluctance in, I perceive that there’s a reluctance in the UK to pick up the phone and talk to social services, because you lose control and they’re useless. That’s the perceived, so part of the education could be actually that social services have a proven track record, even if it’s just in this particular area and therefore it’s more of a, you know, you’re changing the culture and the perception.”

One person had initially been “very wary of social services, just due to reputation.” But now he made much the same point as the family carer:

“Try to get the old-fashioned stories of getting the social involved in the problems radiated, because getting social services involved in my life was the best thing I ever did. Because I reckon people who dread getting social services involved, because they think they’re going to lose total control of everything. They don’t – if anything they actually enhance your control of everything.”

Problems of perception clearly constitute an obstacle to accessing services for people who self-neglect, which individual practitioners must work to overcome. The argument being made by these interviewees is that more proactive efforts to challenge those preconceptions might result in earlier and easier assistance with the self-neglect. However, developing a solid strategy to communicate clearly to the public what services can offer to assist with self-neglect requires services themselves to be clear about it and where responsibility for it lies – something which the interviews with managers showed is by no means accomplished yet everywhere (see Chapter 4).

5.3.2 Implications

The interviewees had experienced a wide range of interventions that attempted to resolve their self-neglect. Some found particular interventions effective to an extent, while others reported that the same approaches had had little success. Immediate needs for housing or healthcare at times overrode everything else. However, there are clear resonances between the views of this group of interviewees and what was reported by operational managers and practitioners, in that focusing on the person and the relationship were seen by all to be key to making progress. Conversely, intrusive or authoritarian approaches were not felt to work well. Different individuals might put varying emphasis on the encouragement they were offered; on how workers saw their strengths or potential; on the extra effort someone made that made them feel that they had value; on the experience they shared with others who provided peer support; or on the practical help provided. But, taken together with what they had to say about how practitioners initially engaged with them, it was significant that a sense of connection with a professional or worker who managed to convey commitment to their welfare was a prerequisite for improvement in their self-neglect.

6. Practitioners' perspectives

6.1 Organisational and occupational contexts

6.1.1 Professional roles

The occupational roles and teams of the 42 practitioners who participated in the in-depth interviews reflected the diverse ways in which services were structured. The invitation had been issued through local authorities holding adult social services responsibilities, but in some locations the invitation had travelled further within multi-agency structures. The diversity within the participants reflects the differing organisational environments in which self-neglect work takes place, there being no one organisational 'home'.

Just over half (22) of those interviewed worked in local authority adult social care teams. The remaining 20 were located in either specialist settings or interdisciplinary teams – including hospitals, adult safeguarding, community mental health or learning disability, re-ablement, long-term conditions, dementia, integrated care and community health – or in other local authority departments such as environmental health or housing. Thirty of the 42 practitioners held social work or senior social work roles; the remaining 12 held roles in outreach/support, care coordination/management, environmental health or nursing. Thirty-two of the practitioners held the professional qualification required for their occupational role, with five of these mentioning additional roles as approved mental health professionals (AMHPs) and/or best interests assessors. Some of them, and also some of the 10 practitioners in roles not requiring a professional qualification, held other qualifications such as teaching, youth work, management, occupational therapy, nutrition and national vocational qualifications. The average length of experience in adult social care or related services ranged from 2 to 21 years, with a mean of 13.7 years and a median of 13 years.

While occasionally giving guestimates about the level of self-neglect work undertaken in their team – “I could say we’ve probably got about half a dozen, about six at the moment”; “some of the older people’s housing support services used to report that about 20 per cent of the people on their caseloads had some level of problem with hoarding” – none gave any formal quantification, and one person identified this as problematic: “We’ve no idea of how prevalent it is as a problem. We’ve learned that there are no studies on prevalence; there are a few from the States, but even those are a bit unreliable.” A few practitioners identified themselves as having a particular interest in such work, but noted that work allocation models were not always able to take that interest into account: “I’d be giving the wrong impression if I said I took the hoarding cases, it’s very much a taxi rank system with allocation.”

6.1.2 Training for self-neglect practice

Practitioners were generally keen for learning focused on self-neglect: “We’re always searching, aren’t we, as practitioners really, for how do you work with people when they don’t want to work with you.” Only 10 of the 42, however, had had training on self-neglect, and this had been on the basis of half-day or one-day courses, in most cases relating to hoarding. For some the training had been disappointing:

“It was quite interesting to get extra information on a statutory framework of who does what, but it wasn’t a day where you reflect at all, soul search around things that you’ve done that could improve next time.”

“I do often find the training is really very basic, it will just scratch the surface of something and they tend to tell you what you already know, if you’ve got a bit of common sense.”

There was also some scepticism about how far training could make a difference, and a preference for policy initiatives that can create change in inter-agency working practices. Eight practitioners, for example, had attended briefing sessions run by their employer to disseminate SCR findings or to provide information on new policy (such as risk management panels). But for one worker, training on hoarding had been illuminating, challenging their previous way of thinking: “We were doing it wrong actually, we were ... enforcing a big clean or something and not seeing it as a coping mechanism that if you remove then there’s no coping mechanism.” And for another it had led to enduring recognition of the importance of relationships: “I suppose what was interesting was just things around patterns, maybe things around relationships.... Those kinds of things have stayed with me.”

Many more practitioners could name training that had some relevance for self-neglect work, if they transferred the learning themselves. This included seven mentions of safeguarding training, five of training on the Mental Capacity Act including the operation of the DoLS, three each of alcohol/substance misuse and addictions training, dementia awareness, and AMHP training, and single mentions of training in mental health risk assessment, counselling and active listening, personality disorder and diabetes.

Three practitioners made links to knowledge acquired during qualifying training, for example, theoretical perspectives that could be applied to assist their understanding of an individual’s situation, albeit with recognition that in a busy working day time for such reflection was limited:

“Basic social work theory – Bowlby and attachment and loss and how important that is, and even Maslow ... that stuff’s really important but sometimes the pressure is that you don’t have the time to do that.”

Eight practitioners mentioned the value of ‘on the job’ learning; the following comments were typical of many more:

“Most of my skills or methods, social work methods to do with this area, have very much been born out of practice, rather than formalised training.”

“I think really the most valuable things that are learned, are actually on the job from my clients, seeing what particular things they respond to and then remember it for the next one.”

Colleagues were seen as an important resource, with exposure to ideas from other professions particularly valued: “I work a lot with district nurse consultants and psychiatric nurses. I think informally I picked up a lot from them.” But so, too, were team colleagues and managers, and those with specialist roles:

“I think it is talking with my own colleagues, and management were very useful, rather than any given training; it is the day-to-day approach with colleagues, with our line managers and safeguarding team.”

Two practitioners valued a discussion forum running in one authority, although they commented that it would be more reassuring for it to have some underpinnings from research. Seven practitioners had undertaken independent reading to extend their knowledge of self-neglect. SCRs were seen as useful in pointing to challenges of communication and inter-professional working, and had influenced individuals' practice: “While I was working with her, [the SCR] massively influenced how I managed that case.”

A mix of these strategies for learning was common, with the following statement typifying many practitioners' experience:

“I've had no formal training on self-neglect, I think my knowledge and understanding of that has been built up from dialogue with colleagues, peer support, supervisory discussions, with a little bit of background personal reading as cases have cropped up.”

Further training was seen as a need: “I don't think there's enough training, we're working in the dark a lot of the time and not knowing whether our interventions are the most appropriate, whether they're going to work.” Knowledge and understanding of law was seen as important: “I think we hang on to law and we need the law to give us a structure to intervene really when things do get ... or to say leave someone. That's what we base that on. So the less grey would be great.” Training for carers and contractors was also required:

“The poor carer said ‘I've got no mental health training’.”

“We have contractors who don't know anything about [self-neglect and the need to] communicate with the other staff.”

“It's not just an environment thing, going in and doing a cleaning intervention, there are social, behavioural issues; I think that's what people don't always understand.”

6.2 Understanding self-neglect

6.2.1 Definitions

Some practitioners, when asked about their own definition of self-neglect, were able to refer to their employer's policy statement, while noting that such policies were a relatively recent introduction in their authority. Formal definitions, where they were given, were clear, if complex, for example:

The inability, intentional or unintentional, to maintain a socially and culturally accepted standard of self-care, with the potential for serious consequences to the health and wellbeing of the individual, and potentially to the community.

Others indicated that such a definition was work in progress and that in the meantime: “Depending on people's experience and professional background, there are different viewpoints of what self-neglect might be within the authority”; “it's open to individuals and individuals' interpretation, which ... is subjective.” Individual

definitions nonetheless encapsulated a number of common strands that add up to a picture of self-neglect; these were the behaviour, the intention behind the behaviour, and perspectives on harm and risk.

Behaviour defined as self-neglect

All the practitioners identified self-neglect as an individual's neglect of their own personal care and/or neglect of their domestic environment – in effect, a failure to take care of oneself in all or many of the essential aspects of daily living:

“Immediately what comes to mind is somebody who doesn’t wash, who doesn’t eat properly and doesn’t deal with their day to day living tasks.”

“... it can include a range of behaviours from lack of self-care to not being able to maintain the environment to hygienic standards.”

“... being unsafe domestically and personally.”

A small minority of practitioners placed hoarding in a separate conceptual category, but the majority of practitioners explicitly ruled it in: “The most extreme self-neglect ... would be my hoarding clients.”

Also included were a number of associated actions that might not *per se* constitute self-neglect, but were often associated with the key features above. These included:

- Actions that place one's health at risk, perhaps by not eating or risking food contamination, refusing medical treatment for health conditions, failing to take medication or excessively using alcohol: “My clients with substance use problems, drinkers and the way that they neglect themselves, they don't keep up appointments, it's very hard to get them engaged with health services.”
- Failure to protect oneself from risks posed by others: “There'll be things like their own awareness of personal safety might not be as in-tuned, so leaving the door open or just being accepting of other people who may not be in their best interests.”
- Rejection of necessary care, perhaps through privacy and independence, or financial concerns: “The people who reject care, especially older people ... and they don't want to pay for anything, even if it's essential for them and they have the money. They're saving for a rainy day and the rainy day's actually here.”
- Impact on others: “It does really impact upon other people that kind of behaviour ... I used to come away thinking, ‘well actually, you have got the right to make an unwise decision, but it is actually very selfish’.” This concern was more pronounced in areas of higher density housing.

In terms of largely excluded behaviours, it is notable that explicit and instrumental self-harm, mentioned by only one practitioner, falls largely outside practitioners' frame of reference.

Self-neglectful behaviours were seen as presenting in various combinations; examples were given of individuals who were self-neglectful in many or all of the above ways, but equally, others had a more selective presentation:

“I’m thinking of one lady who’s a terrible hoarder, she sleeps in her chair, it’s a huge fire risk, floor to ceiling everywhere, but if you saw her down the street, very smartly dressed, very articulate, you wouldn’t think that she was living in that kind of chaos.”

Practitioners were also certain that there is no clear point at which these patterns of behaviour become ‘self-neglect’, that the concept spans a range from low to high intensity, and that factors beyond the behaviour itself determine the extent to which the self-neglect becomes of interest in professional terms.

The intention behind the behaviour

Determining the extent to which self-neglectful behaviour was intentional inevitably engaged questions of mental capacity. Some practitioners excluded from their definition people without capacity, seeing self-neglect as, of necessity, capacitous behaviour:

“My definition of self-neglect is perhaps somebody who imposes neglect upon themselves rather than it being imposed through a physical disability or brain injury or cognitive disability.”

“I definitely would use the term self-neglect if the person has capacity to make decisions about their care needs. I think we need to be making a distinction from those people who lack capacity.”

Mental capacity was certainly thought to be present in many of the self-neglect situations encountered: “99% of people that hoard are articulate, they can make informed choices, decisions.” Others saw further shades of grey, admitting the possibility of more complex interactions between capacity and self-care: “[Some people] have the capacity for doing it, but they choose not to do it, or some want to do it, but can’t because of their other needs won’t allow them to.”

Practitioners were also exercised by whether self-neglect arose from inability or unwillingness to care for oneself: “There’s quite a distinction between self-neglect where a person is physically incapable of caring for themselves ... which is definitely unintentional and self-neglect where a person would appear to have the ability to care for themselves and is not.” Sometimes the term ‘lifestyle choice’ was used to distinguish between the two. But choice was recognised as a tricky concept in itself, engaging moral arguments about whether the extreme situations of the kind encountered in self-neglect practice – situations that invite the response: “Nobody chooses to live like this” – can be viewed as truly ‘chosen’. This raises the question, in effect, of whether there are certain choices that no one with mental capacity could dream of making and where, therefore, either capacity must be lacking or the choice must be challenged or discounted:

“Rather than taking [choice] at face value, [it’s about] not accepting that it’s the person’s choice to live like that; it’s fine if that’s how they like to live, but with [my client] I don’t think it’s how she wants to live.”

Factors sometimes beyond rational control were seen to operate here: “On the whole [people] will tell you they don’t want to be living the way they’re living, that it’s what they’re used to but they’re also fearful of knowing how to change.” Thus, for practitioners, the concept of choice is a moral minefield: “There is an ethical judgement to be made that’s different in every case.”

Perspectives on harm and risk

The key factor that determined whether self-neglect was of professional interest was the level of harm, or risk of harm, associated with the behaviour:

“If somebody has got capacity and they’re making the decision to live in that way, it’s more about whether first and foremost it’s causing them any problems, whether they recognise those or not, are there any risks? Is it causing other people problems?”

Risks could be to the individual or to others, or shared, as in fire risk, or risk to public health. The concept of a needs hierarchy was seen as helpful in determining the level of professional worry:

“So I was thinking of the Maslow table, and our very basic need for food and water and warmth and appropriate toilet ... that’s what I call self-neglect – self-neglect that would lead to possibly serious health conditions or dying.”

The higher the level of harm or risk of harm, the closer it came to ‘very basic needs’, the more concerned practitioners were to find a way to intervene. However, harm and risk were recognised as tricky concepts and to some degree at least socially constructed: “Sometimes, risk is okay; none of us live risk-free lives.” A number of practitioners explicitly referred to social norms as the benchmark against which self-neglect is measured, with the idea that self-neglect is deviance from those norms.

So self-neglect was seen as inherently connected to societal values, and thus risk could be argued and debated, both within and between occupational groups:

“Even within our teams, people have got different thresholds for what we consider needs intervention.”

“Other professionals’ perceptions of self-neglect are different as well, so we have to work with difference of opinion, and it may be that some of our health colleagues would intervene with self-neglect a lot quicker than we would in certain cases.”

Practitioners also talked about the gap between professional perceptions and an individual’s own perception in relation to standards of self-care: “There’s just this inherent tension ... around somebody’s own self-perception of what’s happening and what is our perception.” They identified tension between the need to exercise judgement about risk of harm while remaining non-judgemental about living standards – “Holding that non-judgementalism at the core of your practice is really fundamental” – yet finding an objective yardstick was difficult in contexts that invited the question: “Would you want someone who you know and care about to be living like this?” This involved constant questioning of one’s own values, and balancing one’s own judgement with the perspective of people who use services:

"I think it's recognising your own [values]; it's almost a desire you want to go in and fix everything and saying, you've got to work with what the client wants and what the client needs, so yes I struggle with that."

"It's how we, as professionals, manage how we feel about a situation sometimes as opposed to what we want to do and what we feel we should do."

This also involved questioning the values of others, and resisting pressure when other professionals' tolerance thresholds had been reached: "People are so quick to say 'they can't live on their own, they must be in care' and you've got that fight on constantly; actually they don't particularly want to be in care."

6.2.2 Professional orientations to self-neglect

Workers often appeared quite torn between respecting the autonomy of an individual who is self-neglectful and exercising a duty of care towards them:

"I'm very strong on human rights, autonomy and free will.... But ... it's just that human thing, can you leave someone? Do we leave people in society? You're sort of battling with the level of morality as well."

Arguments for prioritising autonomy, even in circumstances of extreme risk, often related to the perceived individual right to exercise choice: "Some people just live to different standards, they have different lifestyles; that's what they've always done and it's respecting their choice not to do that." Dominant norms underpinning moves to intervene were challenged: "And you have to respect that, you can't take those decisions for people ... sometimes we get so tied up in the perfect lifestyle you're supposed to have and who says it's perfect?" There was recognition that autonomy was inherently bound up with the individual's unique experience of being the person they are: "You can't police someone's personality."

Arguments for exercising a duty of care often related to health risks: "That [behaviour] balanced with quite compromised disability and illnesses ... obviously it does make you aware that there is a duty of care that we have to undertake." So health deterioration for some became the tipping point; "We have no right to judge, unless it's starting to impact on their health and wellbeing, then I think that's the time for intervention." Risks to others were also seen as persuasive: "If I think that that risk is not just for them but also for their neighbours or whatever, then I will try and think of a way to get in there and actually address it." The point was made that in certain circumstances failure to act could constitute breach of a statutory duty and was tantamount to professional neglect or negligence:

"I've certainly assessed people as an AMHP, where people really have lived in horrendous squalor and there was serious self-neglect, and at what point if you don't intervene, does that become professionals neglecting?"

But taking protective action sometimes led to a poignant recognition of the cost to the individual: "He's saying 'you've killed me, you've killed me'; and when I look at him, I think I have a bit, to be honest." Inevitably, what was commonly sought was some kind of proportionate balance between the conflicting imperatives:

“Sustaining someone’s ability to stay as safe as possible, without compromising their character.”

“Try and support her with the highest level of risk so that she had autonomy in most aspects of her life, that we didn’t take that away.”

Practitioners sometimes found it hard to be in a helping profession and yet not to be engaged in positive change; conversely, they were acutely aware that intervening could be driven by their own discomfort, on behalf of society, and that ultimately it may not help the individual.

Vignette: Martha

Here the practitioner takes time to understand the individual’s circumstances in the context of life history; concerns about risks are shared between agencies and a risk management strategy agreed that balances respect for the individual’s autonomy with a duty of care.

Martha is 85. She was eating very little, and didn’t shower or change her clothes. She heated her house by lighting gas rings in the kitchen, creating a fire risk in a house full of accumulated papers, cardboard and other packaging debris.

The practitioner visited on a weekly basis, getting to know Martha, tuning into what was important to her. She also made contact with Martha’s nephew, who explained important parts of Martha’s life history, enabling the worker to understand the significance of her hoarding.

The practitioner took Martha’s case to the authority’s risk management panel, where it was agreed to focus on the fire risks. Smoke alarms were installed, and after several months, Martha agreed to accept a heater and to receive daily meals delivery. She has continued to refuse any kind of care, and becomes angry and distressed at discussion of the state of her home. With the risk panel’s backing, the practitioner has judged that it is sufficient to ensure that Martha gets a balanced diet and uses the heater to keep warm in order to reduce the fire risk, and that to try and force the issue with clearing hoarded materials to which she is very attached would be counter-productive.

6.2.3 Personal impacts of self-neglect practice

Self-neglect work was seen as personally demanding in a way that breaches personal boundaries and engages personal sensibilities:

“I think it’s very emotive as well and you’re entering quite regularly into someone’s personal life and their world they don’t want you to go, so it can be a really uncomfortable place.”

“You have to give a lot of yourself I think to win the trust of somebody who’s not engaging with any other services.”

Although, as the interviews with people who use services made clear, it was often valued when practitioners engaged with them as people and ‘went that extra mile’, empathy could be a mixed blessing: “I find it very distressing seeing somebody who’s really in the throes of that ... I feel terribly for them.” Some practitioners described a sense of personal attachment to people they worked with: “You do become attached, it’s human nature isn’t it? We can’t not get attached to people”;

“It’s not just a job is it?”; “I sort of grew to like him quite a lot and I wanted to do things for him.” Attachment flowed the other way too: “He was very pleased with the will that Age Concern had made for him; then what does he turn around and say? – ‘I’m leaving everything to you’.”

There were times when practitioners found themselves exposed in potentially compromising situations, as a result of the level of their personal engagement:

“Why am I, at 6.30pm when everyone else is at home, here with a washing-up bowl with this 80-year-old lady and nobody else in the world knows that’s happening; that feels very unsafe doesn’t it, somehow?”

This sense of exposure is exacerbated by the isolation of workers who are for the most part working alone in situations where risk evaluations are finely tuned: “It’s very much down to us and our judgement.”

Communications could be difficult and personally challenging: “We sat there and were told we were all liars ... you grow a thick skin”; “There’s nothing I haven’t been called, told or thrown at me, there’s not a lot that I haven’t seen.” There were seen to be physical risks, too, perhaps from the state of a property: “Even if he let me in the property, it wouldn’t be a safe environment to go into.” Risks from infestation were high: “We used to go in and we used to get bitten to death, the carers were getting bitten and they used to keep complaining.” Perspectives differed, with some workers more at ease than others:

“When there was the issue of people shooting up in the property, people were reluctant to go there or they wouldn’t go alone, but ... you just had to have an awareness that there might be dirty needles around.”

Many practitioners talked about the personal emotional impact for them of self-neglect work:

“Sometimes it makes me feel very sad ... one client said ‘you and [my social worker] are like sponges, you come to see me and I give you all this and you soak it all up and then you go away and you’re carrying it’.”

One practitioner described their involvement with one particular service user as “a battle”. Another described being “absolutely overwhelmed by it” as a newly qualified worker; another felt “bewildered by it sometimes, helpless really”. Workers talked about a sense of shock at the conditions in which people live: “I must say my first feeling about this case was I was totally shocked ... it was so, so distressing, it was a shocking experience.” There could be a sense of embarrassment at the very personal revelations contained within an individual’s hoarded material: “I think that was my embarrassment, [witnessing] sexuality [in that way].”

Several practitioners described self-neglect work as the hardest thing they did, with repeated disappointments and frustrations. Running out of ideas was a common experience, and led to practitioners sometimes feeling powerless:

“If someone isn’t coping, I think you have more strength because you have more to work with, you can work with that person to recognise that they’re not coping. Whereas if someone’s choosing not to cope, then what do you work with then?”

This sense of helplessness, accompanied by an overwhelming sense of responsibility, is sometimes intolerable: "It does have an impact on you, so it is easy to walk away sometimes because of the effect it has." Anxiety was a common response: "I was sort of in my state of anxiety and worry and getting probably a lot more involved than I should have been emotionally, that I was thinking somebody just do something." And that anxiety spills over into private time: "It does have an emotional impact ... at weekends, because you never really switch off, I revisit scenarios from every angle and I think 'what more could be done?'" Several practitioners had made interventions to keep people safe, following which the person had died, resulting in self-questioning about whether the intervention had contributed to the death.

Personal responses to the work often prompted reflection on practitioners' own approach to life:

"Maybe it's about me, I daresay it's a personal thing to some extent ... I certainly know what that feels like and it's horrible, so it's a sort of empathy involved I think and some fear, if I'm fearful of ending up like that."

Reflection was seen as an important skill in dealing with one's own feelings and responses: "I've got my own internal ability to reflect and measure whether I need to take a step back." Some workers wondered whether, as a self-protective mechanism, they became de-sensitised to the full impact of conditions: "I think we got used to a sort of certain level"; "I think my personal threshold has become reasonably high." Some described a lessening of impact over time:

"I'm much more philosophical about it I suppose. When I first started I probably would have gone home and thought, 'Oh my god it's my responsibility, I've got to do something about it, how am I going to do it?' But now, I just think, 'Well there's only so much I can do, and it's been going on a lot longer than I've been around, and it will go on'."

"I think it's just you do sort of get hardened to it."

Some, however, described impacts that had brought very negative consequences for them personally, sometimes as a result of engaging with an individual's history and empathising with their extreme suffering:

"That was a traumatic case; that one got pretty dark really. I probably got carried away. I don't know, you just sometimes feel a need to get involved in it perhaps. It made me ill, very ill; it's extremely stressful."

There was recognition of the need for self-protective measures – "I think I'm probably a lot more careful with myself now" – and a commitment to ensure that colleagues have coping mechanisms:

"Realising that this person has got a particular empathy or ability to talk to people, I'll take them out afterwards and say, 'how do you feel after that?' 'I feel tired, I feel drained' 'Okay, how would you get rid of that feeling?'"

Not all personal impacts, however, were seen as negative; in many respects they were seen as part of the job, and the rewards, too, were emphasised: "My bottom

line in terms of social work is sometimes you can't change anything at all actually, but it's something to have had a meaningful human connection." The sense of connection with people was sometimes very strong: "I was extremely fond of him and liked working with him and felt that my involvement in his life ... made his life better, even if only in those moments."

6.2.4 Supervision and support

Given the challenging nature of self-neglect, it is perhaps not surprising that practitioners placed strong emphasis on supervision and support, and saw that coming from a variety of sources – managers, colleagues and at times, friends and family:

"I talk to my colleagues about it, I have got a very good manager, I've got a good life outside of work."

"I just said 'run me a really hot bath and don't speak to me when I walk through the door until I've had it'."

Their practice was also regulated by a range of policies and procedures. In this section, practitioner support is discussed under the headings 'supervision', 'support from team colleagues', 'inter-agency support mechanisms' and 'policies and procedures'.

Supervision

Practitioners' views of supervision, whether provided within or outside of line management, were generally very positive, seeing it as accessible and supportive. Highly valued were opportunities to reflect on the situations encountered in practice, and to gain a sense of containment in the face of powerful emotions: "So supervision is essential, good reflective time to unpick, and slow it down if you can.... So helping people hold that level of discomfort and emotion." For practitioners drawn in to the distress and pain of the experiences of the people they worked with, the need for recognition of the personal emotional impact of the work was akin to that experienced in counselling settings: "For every counsellor ... that counsellor has a counsellor, and that counsellor has a counsellor." Others also commented on the importance of building in such support chains: "I think if you're not supported, you can't support that person." This included at times lending managerial support to an agreed plan, even where that was challenged from another agency.

Practitioners valued the ways in which supervisors could support innovation, either by endorsing an approach being used or by contributing their own ideas: "My manager is brilliant, she ... gives me lots of space to try out new ideas and ... she always comes out with an idea that I haven't thought of." Equally valued was the way in which good supervision can challenge the practitioner's perceptions and approaches, helping to head off an inappropriate 'rescuing' intervention, or to see an aspect of a case that had been missed: "If you've been working with someone a long time, you can get quite desensitised to the risks. You can get almost complacent about it." A different perspective from a supervisor or manager was much valued, and challenge was seen as a key element of the role: "The people supervising us ... need to be able to ask us some challenging questions because if they don't, we could continue not to practise in as safe a way as we would hope to."

Social workers in particular commented on the presence of professional values within the supervision encounter: "I had a supervisor with a lot of integrity, a lot of

social work values and someone who had those at the core of his practice really.” But in mixed discipline team structures, managers may have a different professional background from team members: “You don’t necessarily have social work managers, you may have a manager as a nurse, maybe an OT.” There was a fine balance sometimes between professional perspectives and managerial perspectives on things such as case closure; equally, practitioners may have in-depth specialist knowledge that the supervisor does not. In these contexts the perceived level of professional trust placed in practitioners was helpful.

Supervision did not, however, always allay the sense of isolation and exposure: “Yes, you’ve got supervision but you sit in an office three miles away once a month, not there and then.” Supervision was sometimes experienced as somewhat nominal, possibly somewhat insignificant: “I’d say I and other people are feeling just like an individual in the middle of the desert. So I haven’t felt unsupported but I don’t feel I’ve had any specific support.” For others, it provided a review of cases and of workload, but not a reflective space or an opportunity to engage with theoretical perspectives. It had a more managerial feel to it:

“With supervision, I would say ... it’s like ‘this is what you’re supposed to do, this is what’s got to happen’ [to check] we’ve covered our backs and recorded it appropriately and haven’t gone beyond our role.”

Support from team colleagues

Colleagues commonly provided an informal forum in which to debrief from visits, tell the story, share ideas: “We know the cases that are going on in each other’s caseload, we talk about them and try and think outside of the box.” Such interaction provides an important coping mechanism: “We talk to each other in the office, I think if you didn’t have that, I think we’d go insane some days” – and could fulfil a need for confirmation that an approach being taken was tenable. Sometimes colleagues may be more instrumental in helping to move a case on when the worker felt stuck:

“I’ve in the past taken another worker with me sometimes, just when I feel that I can’t go any further forward with a case, I’ve hit a brick wall; having somebody come in and observing, they can sometimes do something that I haven’t thought about.”

Equally, in informal discussion, a whole range of perspectives could be gathered, a process experienced as motivating and encouraging:

“Every single time I visit, I will come back to the office and I’ll speak to my manager and to the senior practitioner sitting behind me, and to the safeguarding officer sitting opposite me and another social worker sitting next to me.”

A further forum for team discussion was the resource allocation meeting, in which eligibility outcomes and resource requests would be discussed and sometimes challenged. Managerial support for funding commitments that were out of the ordinary, in order to accommodate a care package with which the service user would engage, was forthcoming in some examples given, demonstrating flexibility that practitioners strongly valued. Similarly legal advice, when requested, was forthcoming and helpful, although may be rationed: “We have to be very careful how often we use it; we have to go via a management decision to be made.”

What was sometimes missing for some practitioners was a more formal opportunity for team review of cases and casework, particularly from a multi-disciplinary perspective:

“There are quick discussions and we’re a very supportive team ... but I think a real case discussion to really unpick ... because then you can really look at what worked and what didn’t, what was good practice and what could have been good practice.”

Shared clinical discussion was more common within multi-disciplinary teams, where practitioners experienced them as helpful; on occasion they resulted in explicit categorisation of the risk levels in individual cases, in order to facilitate the most appropriate response across the team should an alert be received.

Inter-agency support mechanisms

In some authorities, well-established and effective safeguarding networks were available to be used in respect of self-neglect cases:

“Under adult safeguarding, if there’s a case where somebody’s self-neglecting, they can be brought in if the team decide to call a professional meeting, as opposed to just working on a one to one level.”

In others there existed a separate forum for discussing particular cases that were of potential concern, either because individuals were at high risk in the community due to their self-neglect – perhaps showing ‘high vulnerability’ due to risks of a particular nature such as fire, or clinical mental health – or because they showed a pattern of revolving door admissions to hospital with little engagement in therapeutic work in between. Such discussion was intended either to bring coordination to the involvement of different agencies, or to secure continuity of approach between hospital and community, in an attempt to address lifestyle issues impacting on health. Typical membership might comprise adult social care, housing, environmental health, the fire service and psychology. Part of the value, from those involved as regular members, was to clarify the role of different agencies, and to ensure all options, including statutory options, were considered in any individual case referred. It was thought important not to set eligibility criteria for referral to such a panel, but to allow referral at the practitioner’s discretion. The intention was not to create off-the-peg solutions, but to share ideas: “People have got quite high expectations that we will come out with solutions; we won’t. We will come out with some ideas ... different things to resolve it.”

Perhaps as a result of high expectations, practitioners’ experience of panels was mixed.

“We talked about what we were doing and what we’d achieved and they responded, ‘yes we think you’re doing the right thing’, but I didn’t come away with any new tools to use.”

“I was very disappointed ... there needs to be some sort of regular review of what’s happening, but that certainly didn’t happen; I was really working totally autonomously.”

Sometimes discussion was felt to be dominated by one particular perspective:

“They’re quite powerful environments to be in and it’s quite hard to challenge health, if you’ve not got the confidence or experience to do it.” For one practitioner, however,

taking a case to the panel, despite not resulting in any new approach, had at least provided some kind of 'permission' for her continued involvement, should anyone challenge her ongoing involvement. For a few others, it had stimulated other agencies to sit up and take notice, acting as a lever to secure engagement in the case. In one authority, an informal network of practitioners from different agencies met to discuss the challenges arising from hoarding in specific cases, seeking clarity on what could and could not be done, and valuing the reassurance of a shared perspective:

"People found that really helpful to understand what the abilities and limits of other services were. Also a lot of services have felt they've been trying to deal with it on their own ... so people found it really reassuring, and you had to accept that it would be a long slog sometimes."

Another type of inter-agency forum was built into routine work practices through a weekly meeting attended by hospital and community health services as well as by dedicated workers from adult social care, to discuss people with high frailty scores, including many who self-neglected. The value here was seen as being the integration of the care pathway that could emerge from a shared understanding and clear planning, and the reassurance of sharing responsibility with others. "You do start worrying about people, and you get quite anxious for them and the risks they impose on themselves ... I suppose it's about sharing that responsibility as well."

Policies and procedures

In some authorities the multi-agency risk panel sat within a multi-agency policy on self-neglect, or was accompanied by guidance on self-neglect practice. Such policy/guidance documents were in general terms viewed benignly by practitioners, albeit with a touch of scepticism: "They're based on the right principles, but it'll be interesting to see if they can be carried out to the letter in practice." Statements endorsing the sharing of information were seen as facilitating inter-professional working:

"The new procedures acknowledge the need for consent for information sharing, but in the cases of high risk it seems to come down on the side of sharing information anyway, and that comes above client consent."

They were also seen as potentially helping to engage agencies that were sometimes experienced as difficult to engage, or liable to close cases while still unresolved: "It gave us the mechanism to really insist that our partner agencies work with us, rather than us doing it all." The role of policies and procedures in achieving some kind of consistency of practice was also thought to be helpful.

Conversely, a number of practitioners were not sure whether policies existed, or were not familiar with them, and a few were concerned at the potential over-proceduralisation of practice: "I can't see how that would benefit the person but I can see how it would mean an awful lot more filling in of forms." Mentioned as helpful by a few practitioners was a practice 'toolkit' that had been developed from research findings, and in which some confidence could therefore be placed.

In other authorities, there were no specific policies, procedures or guidelines on self-neglect work: "You're working in the absence of a specific policy or protocol around working with people living in squalid conditions or working with people who hoard."

Here and elsewhere, however, practitioners mentioned a range of tangentially relevant procedures that were available to them, including safeguarding procedures and mental capacity guidance.

6.3 Self-neglect practice

A central element of the interview with each practitioner was the account they gave about their practice in cases of self-neglect. The 42 practitioners between them described 122 situations in which self-neglect was a feature – some in greater depth than others, but all illuminating some aspect of practice that could contribute to beneficial outcomes. The individuals involved were most commonly older people, but there were examples from across the age range. The work had been initiated in numerous ways, with no sustained pattern of referrals, which came from a wide range of sources – hospitals, GPs, police, fire and ambulance services, nurses, sheltered housing wardens, day centres, other services within adult social care, neighbours, family members and a café owner. In some cases a safeguarding alert had initiated the referral, although the work was predominantly led from teams within adult social care.

The analysis that follows first describes the forms of self-neglect featured in the cases, considers associated factors, and reveals how practitioners understood the self-neglect. It then discusses the processes of engagement between the practitioners and the people who use services, identifying the approaches used. Finally it outlines the interventions made and, where known, the outcomes, concluding with practitioners' reflections on the kind of practice that can achieve beneficial outcomes.

6.3.1 Self-neglect in the practitioners' case narratives

As with the interviews with the people who use services, the practitioners' accounts confirm that there is no typical self-neglect case. It is, however, often the case that either neglect of self-care or neglect of one's surroundings was the dominant feature, although often the two were combined.

Neglect of self-care

Personal care

Practitioners described people who neglected their personal care in often extreme ways. Total lack of attention to personal hygiene, through not washing or bathing, not changing clothes and bedding, incontinence and soiling, and not cutting hair or nails, often resulted in a dirty, unkempt appearance: "His clothes were falling off and he couldn't do them up, and he had long hair which was very matted"; "The flat was an absolute pit, it stank of urine." Some described those who had withdrawn to their bed and who were incontinent: "He's not going to the toilet at all so there's faeces and urine everywhere." Over-powering smells were frequently mentioned.

There would sometimes be little evidence of food:

"We couldn't make out ... when was the last time she'd had something to eat."

"There was absolutely no food in the house whatsoever; there were tin cans that she had obviously used and then put the empty cans back into the cupboard and that was all that was there."

Or the food consumed would be unrefrigerated, mouldy, rotten or composed of leftover scraps. Sometimes insufficient fluids were being taken. In extreme cases, an individual might be living on rotten vegetables and road kill. Physical comfort was sometimes totally absent: “She would sit regularly in the dark and in the cold”; “He tends to sit [outside] through the night in freezing cold weather and ... he’d not had heating for decades or lighting.” Sleeping on newspapers, on a very soiled mattress or in a chair was mentioned in a number of cases. Some homes were very bare and sparsely furnished – “a very dirty, bleak environment.”

These combined factors had, for some people, resulted in malnutrition, skin breakdown and pressure sores and dehydration, requiring hospital admission, sometimes on a repeat basis.

Healthcare

Neglect of healthcare was also a form of personal self-neglect, with numerous examples of failure to consult about medical conditions, to take prescribed medication or to keep dressings in place, along with rejection of treatment offered for diagnosed conditions. Lack of oral hygiene led to severe dental problems. Health risks as a result of diet were also apparent, with examples of both massive weight gain – “She’s very, very overweight; she’s not able to go out because she’s so big” – and anorexia – “She was painfully emaciated”. Concerns were expressed that digestive disorders were sometimes related to eating contaminated food, or to failure to prepare and cook food hygienically.

Self-neglect of health often involved excessive use of alcohol, both as a daily lifestyle resulting in liver disease or other conditions, and on a binge basis, where the individual would “collapse on the pavement in urine-saturated clothes and be taken to hospital.” Unlawful drug use featured in one or two cases, particularly involving younger people, but was much less common; health neglect through chain smoking was common, however: “In there all was completely sepia; even the paintings on the walls were completely stained from it.” In addition to the long-term health implications, alcohol and smoking brought additional, immediate risks, such as falls and fractures in the case of alcohol consumption, or risk of fire in the case of smoking:

“She smoked very, very heavily and the flat was full of rubbish, and particularly papers and newspapers and magazines. There were cigarette burns on all her bedding, on her night attire, and ... on one occasion she had six cigarettes on the go at one time, and ... they were all around her smouldering among the papers.”

Neglect of environment

The second key feature of self-neglect in a large number of cases was neglect of the environment. There were two major patterns here – hoarding and squalor. They sometimes occurred together, but equally there were examples of hoarding in an otherwise clean domestic environment, and of general squalor without explicit hoarding.

Hoarding

The hoarding described by practitioners took many forms, but typically showed extreme accumulation of a wide range of materials: books and newspapers, scale model kits, collectables, personal memorabilia, bicycle and motorbike parts, building

materials, industrial equipment, scrap metal and wood, old fridges, food and food packaging, junk mail, plastic bags, medication, shopped items, items for recycling, and plastic boxes. The accumulation had built up in different ways, with broad patterns being either omission ever to throw anything away, resulting in extreme clutter from often dirty and soiled domestic items, or the explicit collecting of materials brought from outside the home. In both, it was common for the individual to have difficulty moving around inside their home due to the hoarded materials: “Narrow walkways through the stuff to a chair in the kitchen and to the staircase”; “He was just living in a kind of burrow that he’d made in the middle of it.” The materials themselves could be stacked in ways that posed severe risk – “Floor to ceiling in every room” – or required the individual to clamber over piles, or to crawl on hands and knees: “And on the top was almost like a nest, literally maybe a metre away from the ceiling where she was sleeping.” The individual was sometimes confined to living in one room, or to the hallway, and access to the building from outside was sometimes impossible.

Squalor

Many individuals known to the practitioners lived in conditions of extreme dirt and filth. The conditions had often built up over many years without cleaning having taken place, rooms almost returning to nature: “a gossamer of cobwebs over the whole environment”; “He never used his bathroom, his bath was black, I don’t know how it got into that condition, his sink was too and I don’t think his loo worked.” Furniture was sometimes falling apart and was threadbare. Utensils and crockery in use were encrusted with mould. Food accumulation contributed an additional dimension: “She would have rotten food in the kitchen, so then you’d have flies and maggots and all the things that go with that.” Sometimes domestic animals were present, and were not being cared for or given appropriate facilities, with resulting animal soiling throughout the home. Wild animals might also be fed in the house. Squalor (and sometimes hoarding, too, depending on the nature of the hoarded material) led to infestation with vermin, insects and birds – rats, cockroaches, fleas, maggots, flies and pigeons.

Poor housing conditions were common, particularly where property was owner-occupied or belonged to a private landlord. It was thought that people who hoard are not seen as desirable tenants, and find it difficult to secure any agreement to major repairs from landlords. In one case, raw sewage was leaking through a ceiling from the bathroom above. Other examples demonstrated very problematic structural issues:

“It was decrepit and falling apart around him – literally there were holes in the walls to the outside world.”

“A rented house that was literally falling down, infested with mice, filthy dirty, mouldy.”

“Evidence that pigeons had got into the property, gaps in the flooring, gaps in the walls, it was very, very run-down and neglected.”

Neglect of the environment could extend to the exterior of the property. There were examples of hoarded material, and infested matter, spilling outside, and of overgrowth outside: “So I could see No 44 and No 48 but [not] the house where she

was living; the plants were totally overgrown and it was completely out of the picture.”

Fire risks around hoarded material were very commonly noted: “It was a fire waiting to happen, it was quite frightening”; “He lights the gas rings [for heat], and there’s cardboard everywhere so there’s big fire risks.” Sometimes hoarded material might be piled around the fridge and freezer, resulting in fire risk from red-hot compressors. The risk was further exacerbated when exit routes from the property were also blocked.

Vulnerability to others

It was sometimes the case that the self-neglect took the form of self-exposure to risks from others; in fact, a safeguarding alert was sometimes the reason for referral to adult social care.

Some individuals were known to have difficulty protecting themselves from possible exploitation in social relations that were potentially abusive:

“He was being targeted by young females who would talk their way into his flat, use his telephone, run up the bills, put him into debt. He was either freely giving away his giro to them, or they were taking it.”

“He had people who were homeless squatting with him, and they all drank a lot of alcohol together. He had money taken from him.”

Similar circumstances related to involvement in networks of people using drugs: “She hangs out with people who also drink and take drugs ... people come to her and so she’s vulnerable in her own home.” In some cases it was the state of the property itself that created the potential third party risk, with the service user refusing to get repairs done: “His door, the windows are broken and he just puts his hand in ... everybody knows in the neighbourhood that he doesn’t use the key, so he’s very vulnerable in that respect.” Sometimes a property might be targeted for break-ins because it looked derelict.

In a number of cases there was evidence that adult children were taking money from the individual, and/or that they were being bullied within their family. Often, however, any safeguarding action was frustrated by the service user’s insistence that they agreed to the actions in question. Even where safeguarding intervention was possible, the outcome was not straightforward; one example told of a learning disabled man whose decline into self-neglect followed directly from an intervention intended to keep him safe from abuse by a family member in the shared home.

There were also situations where two people in a relationship – marriage, parent/child – were involved together in complex interactions of self-neglect and neglect. Examples included one individual caring for his disabled wife but refusing to allow the house to be heated, or to buy sufficient food, and failing to give her fluids. Another involved an older woman confined to her bed and unable to use the stairs but receiving care from her son in a grossly neglected domestic environment.

Emotional and cognitive responses

Practitioners sometimes reported the individual’s own perception of their self-neglect, or of the circumstances in which it occurred.

Vignette: Ron

Here the practitioner recognises the depth of feeling that can accompany self-neglect, and acknowledges this. Acceptance of some basic safety and comforts is negotiated, without seeking major change; there is good communication with the care team about the emotions experienced, and a shared risk assessment.

Ron is 75 and has early dementia. When he was diagnosed, the psychiatrist noticed that his clothing was several sizes too big, so he must have had considerable weight loss. The social worker did a joint review with health and found the property very dirty and neglected, with evidence that Ron's diet was very poor. Ron didn't see any of it as a concern, and consistently asked workers to "Leave me alone, I'm an old man. I'm ready to die."

He has, however, accepted some daily care. Some of his carers get alarmed when he says things that sound despairing, but the social worker has shared the risk assessment and reassured them that Ron is expressing how he feels rather than declaring an intent. When Ron says "I don't want to be here", the social worker recognises the depth of his feelings, and acknowledges what it's like to feel that way, and Ron seems to really appreciate that honesty. The social worker doesn't push Ron further; he has the minimal care he needs, and that keeps him safe and living at home, in line with his wishes. His mental health is monitored, and the goals set are proportionate and realistic.

Denial

Where the self-neglect was around personal care, the most common observed feature was a form of denial by the individual: "She soils herself and wets her clothing, so she's incontinent and seems to be aware of it – her hands and her face, everything is soiled – but she ignores it in conversation." Professionals' concerns would be swept aside: "She said 'there's nothing wrong.... I lived on a farm years ago when basically we didn't have a flushing toilet'." Sometimes the service user would claim that the state of the home was just today, and that things were not usually like this – giving the impression that everything was under control was important to them.

Acknowledgement

Conversely, where neglect of the domestic environment was a key feature, people were often said to be acutely aware of this being problematic, and were both embarrassed and ashamed:

"He said 'Oh look at this place, I know it's an absolute pit, I know it's disgusting, I'm ashamed of it'."

"We got to the bathroom and her comment was, 'I don't want to show you in here, I'm ashamed'."

Embarrassment about the state of the house itself could impact on whether more structural matters could be dealt with:

"She's not allowed the council to do repairs on the kitchen and bathroom ... the building looks like it's got cracks in it. She wasn't allowing people in just to do basic things because she was too embarrassed about the house."

Sometimes they were fearful, too, of the judgement of others: “If an envelope came through his letterbox, he would just tremble for days before he opened it because he would think he’d been found out; he feared the council terribly.” Sometimes denial and acknowledgement co-existed, relating to different aspects of a complex self-neglect picture: “He saw the fact that his flat was full of stuff as a problem. With regards to him eating old leftover food, he doesn’t really see that as a problem.”

Pride

Sometimes pride was a dominant factor, overriding other emotions and other factors such as the need for personal care or domestic help: “Being self-sufficient and self-determining was massively important to her.”

Blame

Sometimes people would blame others for their situation rather than bear responsibility personally; this seemed particularly to accompany heavy use of alcohol: “[She says] he’s absolutely to blame for her drinking and he does bring the drink round for her as well.”

Rationalisation

Practitioners reported a sense of rationality in service users’ explanations of their neglect of the environment:

“I said ‘why is your home like this, what happened?’; her excuse was that ‘oh I had a flood upstairs, from the top flat’; ‘well I can see that the ceiling has been re-plastered, that’s okay, so why are the clothes, everything on the floor?’ ‘I want to get a new wardrobe’.”

A collection of margarine boxes was easily rationalised: “She would say when she took the dog out for a walk and if the dog got hungry, she’d put the little snackettes in there, it was all quite plausible.” A common rationale was that the materials were being kept for recycling or for making things with: “He’s always been handy ... always been able to make things, so you have to keep everything in case it comes in handy.” Some were reported as describing their collecting as a family trait: “a bit of a genetic issue”; “he’s saying all his family collect things”. Others expressed a rationale for their own behaviour based on their history: “I know I do this. I do this because of my experiences in the war, I never had anything, everything I had was taken away from me.”

Resolve to change

A resolve to change things was sometimes expressed, but usually didn’t bring results: “He’s been saying ever since we first made contact that next week ... he’s going to get it all cleared out, but it certainly seems that that next week is never going to arrive.” Some had been explicit about the significance of the hoarded materials: “He’s talked about his property not feeling like a home if it’s all taken out” – and the hoarding behaviour was seen as stronger than the stated intention to change:

“He was full of motivation for how he was going to sort it out ... and as we went along, he couldn’t stop himself picking up glass bottles for recycling and things for recycling to take into his house to keep.”

Links to health or disability

The practitioners' case accounts often referred to factors in the lives of individuals that were linked in some way to the self-neglect, although it was sometimes difficult to distinguish between factors that were incidental to the self-neglect, factors that might have some causative influence, and those that resulted from the self-neglect.

Learning disability

Practitioners noted varying degrees of learning disability in the people they worked with, although in no cases was this cited as a reason for the self-neglect. Levels of literacy were sometimes mentioned, although sometimes arising from educational disadvantage rather than learning disability.

Physical health

A number of people were described as having physical health that was compromised in some way. Specific conditions included speech and mobility loss following stroke, chronic physical health conditions, deep vein thrombosis (DVT), neuropathy, visual impairment, diabetes, asthma, anaemia, chronic obstructive pulmonary disease, cancer, liver disease, Parkinson's disease and ME. In many cases, the health conditions were not the central focus of adult social care intervention, but practitioners did sometimes express concerns about how health issues were being addressed, giving examples of repeat prescriptions continuing to be issued without checks on their use, enabling a service user to stock-pile large quantities of powerful drugs, and the prescribing of drugs without clear medical reason for their ongoing use.

Alcohol

As noted earlier, longstanding, excessive use of alcohol was a pattern for many individuals and indeed, in some cases, had continued through family generations. Its role is complex, certain patterns of alcohol consumption being seen as a form of self-neglect (thus mentioned in an earlier section), as well as causative of other forms of self-neglect relating to personal care and the domestic environment (thus to be mentioned in a later section too). Here, the focus is the extent to which the alcohol consumption was seen as a marker of a general lifestyle in which other forms of self-neglect, such as poor living environment, were also apparent; a number of practitioners observed this association in single men in late middle or older age, but there were also examples of women whose use of substances was deeply problematic for their safety: "She'd been admitted to a burns unit for a severe burn that had occurred a day previously; she'd been so intoxicated she hadn't responded to it appropriately." Alcohol use was also sometimes accompanied by a somewhat chaotic lifestyle, and talk of suicide.

Mental health

Mental health was a feature in some cases, sometimes with clear and established diagnoses such as schizophrenia, personality disorder, autism, bipolar affective disorder, dementia, Korsakoff's syndrome, anxiety or depression: "He'd been in hospital under the Mental Health Act ... he'd attempted to take his life, so he was very depressed, very stuck, and it looked like the world had almost stopped." Paranoid beliefs and suicidal ideation, whether or not accompanied by diagnosed mental illness, were both also mentioned. Mental Health Act assessment (of the

need for hospital admission) had sometimes taken place, but had not always resulted in admission.

Practitioners were cautious about the interface between mental health and self-neglect: "If you've got someone with acute mental health needs there are certain ways of trying to help someone in that situation that are going to aggravate whatever's going on for them." Equally, it was recognised that symptoms of apparent mental disorder could arise from self-neglect, for example, where severe dehydration could present as confusion.

Links to life histories, family and social relations

The practitioners were able to talk about the past lives, and the past and present social relations, of the people they worked with in some detail, evidencing the lengths to which they went to try and understand the context in which the self-neglect was occurring. Even where people remained a closed book in that respect, practitioners commented on this as an absence in their understanding. The importance of what had gone before was not to be underestimated: "On a lifespan diagram, if you were to map it out, social services and multi-agency input coming into his life on that lifeline was tiny in terms of timeframe."

Life histories

Past life experiences often included life-changing events. A few of the individuals whose stories practitioners recounted were Holocaust survivors and had travelled to the UK as young people after the Second World War; others had endured other traumatic circumstances, including separations and torture, during times of war. There were examples of abusive relationships – sexual and physical abuse as a child or as an adult, from which sometimes an independent path had been sought – "Her husband had a chronic alcohol problem and she decided to leave him once her children were grown" – and of the loss of a child about which the individual remained devastated. A number of individuals had grown up in care; another had lost her children to the care system.

For others, their past was defined by employment that they had loved: "He'd worked with cars, he'd done quite a few different jobs and he really loves talking about when he was busy and employed"; "He'd had a job he really treasured, selling newspapers". Others had held positions of responsibility in the professions, or in politics, writing or business. Often what was conveyed from exploration of past life was a sense of independence and achievement: "She was very, very independent in her thoughts to get to where she was."

Talking about the past sometimes surfaced a different dimension of the individual's personality, in counterpoint to their usual presentation: "If she talked about the past she'd light up, it was great." Equally, some seemed able to talk willingly about the past but would not tolerate conversations that focused on the present circumstances in which they lived.

Family relations

Family relationships in the context of self-neglect were both positive and negative features of people's lives. It was not unusual for individuals to be living in the home that had been shared with parents and siblings during earlier phases of their lives, surrounded by the embodiment of a shared family history: "He's from quite a big family, but all his siblings have trickled away." Others, by contrast, were very

disconnected or estranged from family, perhaps by history, by geography or through their behaviour.

Family bereavement was often spoken about, and cast some light on relationships that had been deeply valued but were perhaps more problematic in the context of the self-neglect:

“When he did talk about his wife, he did actually tell me he couldn’t bring himself to give her clothes away. So he almost had a kind of mausoleum of her clothes in the wardrobe and couldn’t part with them.”

Some narratives showed a level of co-dependence between individuals; there were several situations in which an individual with health or care needs was being cared for by an adult child or partner who was self-neglectful. There were examples in which it was difficult to disentangle one person’s hoarding from another’s: “It transpires that he is hoarding his stuff in her flat.” Reaching understanding of such inter-relationships was a complex process; in one case it had been assumed that a husband was neglecting his disabled wife, whereas in fact, it was she who was refusing care.

As noted earlier, there were a number of examples of money flowing to adult children in circumstances that could entail financial abuse, but where the individual maintained that the money was being given away. The reasons here were sometimes complex, related to self-esteem: “He insisted that he was choosing to give this to his children because he was a bad father and it was his way of making it up to them.” Another individual, with his worker’s support, had objected to the financial abuse, and as a result his daughter had ended the relationship with him.

Family relations were sometimes described as deeply fractured. One individual was exposed to “constant anger, threats of violence, and things like that from her daughter”, who lived with her. For another, “the brother was going round to the property and financially abusing the mother and using the flat to inject drugs.” Childhoods had been troubled:

“She was sexually abused as a child followed by [further abuse] as an adult.”

“She’s not had much of a chance since she was a child; she was kept off school a lot, I think ... because her mother wasn’t looking after her properly and didn’t want to get into trouble.”

One woman whose children remained at home experienced bullying and physical violence: “Just very angry because it’s so full of junk and they smash the things up.” Some were in volatile partnerships or ex-partnerships in which alcohol would fuel crises involving violence and refusal of access to the home, or even eviction.

There were examples of disengaged relationships that, while not overtly hostile, were characterised by a degree of ambivalence. One person was being financially abused by one brother in acts that were condoned by another brother. Another was supported, but only at arm’s length: “He had brothers who kept an eye on him, but ... they were often in a position of not speaking to him.” In other cases the individual had had a close relationship with one family member, whose death had resulted in changed dynamics that were less supportive: “She was very much left to fend for herself and broke away with tradition of family.” There were a number of examples in

which an ex-partner was still involved with the individual, helpfully sometimes in practical terms, but equally difficult dynamics of the relationship, sometimes involving domestic violence, remained in place.

A number of people were described as having more positive links with members of their family. Some were supported to manage finances, or family members undertook that role for them: "The daughter was very scrupulously honest and acting in her best interests." Support was sometimes provided at long distance, but was nonetheless understood to be important to the person at an emotional level, or in encouraging some degree of self-care. Even where family relations were positive, they were sometimes not sufficient to act as any kind of protective factor. "They are trying to support him, kind of from afar because they're living abroad, but not even his children are a safety net."

Social relations

While many were very isolated, others were well connected in their local communities: "He knew lots of people in the block, having lived there for ages and having had a dog, and the local shops knew him well"; "she goes out to eat in a café and she's got a cohort of friends". There were examples of social relationships that had a clear function in terms of helping to manage the self-neglect: "If his landlady really encouraged him, he'd go and have a shower or change his clothes, and she did his washing ... she was providing food." On several occasions befrienders were involved in providing a degree of social interaction and support.

Sometimes their connections, while positive in the sense of providing companionship and a sense of community, were also focused on activity that was not so good for their wellbeing, such as drinking. They sometimes also verged on exploitative relations (as explored earlier in relation to vulnerability to others). A further complication was sometimes that behaviour was experienced by neighbours and those in the locality as problematic, and at times created hostility:

"She can be inappropriate at times and be quite rude as well, which can get people's backs up ... when she's unwell she's very suspicious of people so will accuse people of things, when she's throwing items out of her property."

6.3.2 Practitioners' understandings of the self-neglect in the case narratives

Self-neglect was recognised as an intensely personal experience, with a unique constellation of factors in each individual case: "There's always, always a reason behind why people self-neglect." At the heart of practice, therefore, was a search for that individual experience and an understanding of its significance to the individual concerned, in essence a search to find the 'self' in self-neglect: "Self-neglect is such a personal issue, and when you start to broach it in people's lives you're having to shine a mirror on something they probably don't want to see at all." The practitioners spoke with openness and compassion about the lives of the individuals with whom they worked in sometimes the most difficult of circumstances; a number of key themes follow, which emerged from their accounts of how they made sense of the self-neglect they witnessed.

Recent change or longstanding pattern

Two patterns emerged in relation to how practitioners understood the 'self' behind the self-neglect, differentiating between two types of manifestation. On the one hand,

they encountered people whose behaviour represents a relatively recent change of living conditions or approach to life – “This may be not how they’ve always lived, so the identity of the person, has that changed as well?” On the other hand, are those who have always to some extent shown a particular behaviour, which has now become more problematic either because it has intensified, or because changed circumstances make it impossible for them to express the lifestyle choice:

“They’re people who [could be described as] eccentric; they’ve lived as much as possible outside some of the norms that the rest of us apply... but perfectly successfully.”

“... strange or abnormal beliefs about the way to live.”

Both could arise from change in health status, or traumatic event, but may have differing significance for the individual. Both were seen as understandable. Recent change may be related to health diagnosis: “He was going to die; we actually thought that this might have been the reason for his self-neglect, and his lack of interest in taking care of himself.” Such recent changes were in some ways seen as more approachable than circumstances in which an established lifestyle choice has become more extreme:

“When the traumatic event has intervened, or just accumulation of chronic conditions has intervened and they get to the point where they can’t be so independent, then all that matters in a way that it hasn’t before ... they were private individuals who can do what they like ... so you’re trying to make the person who, for 50/60/70 years has trod very much their own path, into somebody who fits into a system.”

So identifying whether the behaviour constitutes a recent change or a longstanding pattern was part of the practitioners’ way of understanding the self-neglect: “That’s what I meant about their identity. If they could see themselves now would they want that to change?” In some cases, the behaviour was so much part of the individual’s self that removing hoarded material, for example, was recognised as “like ripping their skin off”.

Past life trauma

Practitioners often made sense of self-neglect by referring to past trauma in the life of the individual, although the mechanism by which knowledge of past trauma helps make sense of present self-neglect was not explicit in their accounts. Experiences during war were sometimes explicitly referred to as influential for the individual. This could relate to different roles held; several people had survived the Holocaust and carried that trauma of that experience with them; equally experience in the armed forces was influential: “He talks about being in the Army, some of the experiences that he had will have made an impression, I think he’s got very deep, hard-wired problems going back a long way.” In respect of others, practitioners recognised the trauma of an abusive childhood, with sexual abuse as a child being followed by further abuse as an adult, both sexual and physical in a number of cases, and also experiences of being neglected as a child.

Self-esteem

A further feature of practitioners’ understanding was recognising low self-esteem on the part of the individual: “He has a thing about wasting money on himself because

his self-esteem is extremely low.” This was often seen to stem from earlier life experiences, either right back in childhood or as a younger adult. In some cases self-esteem was hampered by the individual feeling they had been a ‘bad parent’ or were ‘bad at relationships’; in one case, their children had been taken into care, and in another they had been through court action: “The father of her son took her to court to try and get custody of the child, and that had a big impact on her; it made her feel worthless.” Several people were said to have lost contact with their adult children. Others had had difficult experiences as children themselves – growing up in care and being abused in that environment was seen to have been as damaging to self-esteem as the family circumstances that led to care in the first place, leading to a sense of total abandonment. Sometimes people were seen to hold more esteem for animals than for themselves: “they tend to care more about animals than human beings or themselves.”

Loss

Loss of people who had been loved and to some extent relied on for security and containment was also very evident in the practitioners’ understandings of self-neglect: “Sometimes for men who love their mums, when their mum passes away, that’s when they have that loss and then they start holding onto all this other stuff.” Many of the service users described were thought to be experiencing deep sadness through loss of close relationships. The loss of valued roles that had contributed to sense of self-worth was also significant: “Clients tend to talk mainly about the people that they’ve lost in their lives ... and then secondly loss of role, loss of work, all those loss related things.” Sometimes the hoarded material was understood as having deep significance in relation to the loss:

“A lot [of the items] were connected to his previous employment.... I got the sense that it was very much part of his identity. He was trying to hang on to that identity, rather than someone who’s on his own because his wife had died.”

This sadness could be accompanied by depression: “He’s typical of someone who’s very depressed, I think, and he’s experienced a significant loss.” One man had sunk into deep depression following the death of a friend, who had died on his sofa, and had been unable to dispose of household rubbish since that time. Others had experienced multiple losses, of parents, siblings and children.

As well as bereavement, the loss could entail separation or divorce, and the experienced loss of a shared life history with the other person: “She talks about the past, how she helps her ex-partner build up a business.” Such fractures were sometimes seen to link directly to the self-neglect:

“His wife reports he was incredibly abusive, but it got to a point where ... she left. And that has just triggered this downward spiral; he’s hit rock bottom where his self-neglect has got to the point where he can’t even move out of bed.”

In some cases loss had tipped the balance, resulting in a previously manageable behaviour pattern spiralling out of control: “I think he drank quite heavily in his working life, but it had got out of hand and when his wife died.” There could then ensue a slippery slope in which the alcohol use caused lack of personal care and incontinence, subsequent organ failure, causing immobility and then further health problems.

One response to the loss could be de-motivation:

"I got the impression something irrevocably had gone off the rails, either within a relationship or a bereavement, or a loss of role or of status. The person feels like they will never ever regain what they had. And that therefore everything else is bothersome, irritating and they just don't want to get on with it."

A coping mechanism

Sometimes self-neglect was understood as a coping mechanism.

"We were enforcing a big clean and not seeing it as a coping mechanism that, if you remove it, then there's no coping mechanism ... I now see that sort of action as completely counter-productive, as well as potentially rather abusive."

Sometimes self-neglectful use of alcohol was understood as a means of coping with an undesirable reality:

"They feel railroaded into something that wasn't what they had in mind; he didn't drink to enjoy and sit ... he drank to just become unconscious. He had a race with drink; he would just drink to be taken to hospital, because he was just at the end of his tether."

There were also examples of individuals who had turned to alcohol to deal with the pain of unhappy experiences, perhaps in childhood: "He started drinking because of an unhappy childhood, he was essentially in care and [there's] something about him that's very sad ... you don't feel sorry for him but ... his vulnerability is very palpable."

Alcohol

Alcohol addiction itself figured large in practitioners' understandings and, as noted earlier, in addition to being seen as a form of self-neglect of health in itself, was in some cases seen as the underlying cause of other forms of self-neglect:

"He drank to a point where he didn't wash and would ... be completely inebriated, needing carers to make sure his continence needs were managed.... He wouldn't undertake any self-hygiene routine at all."

The alcohol was seen to take over, becoming the most important feature of daily life, and leading to a blunting of awareness about other features such as self-neglect of the person and squalor.

Control

Practitioners not infrequently mentioned a need for control as underpinning some forms of self-neglect, particularly related to hoarding: "He had OCD so he was immaculately clean and controlling and ... very controlling of his wife too. When she left, he started the hoarding behaviour."

A means of communication

A few practitioners gave examples in which they understood the self-neglect as a form of communication by the individual. In one case the message was understood

as expressing rebellion in the face of circumstances the person had not chosen and had no power to change:

"I think his self-neglect was very definitely how does a completely disenfranchised person express disapproval? They can only do it with what's at their means and what was at his means was his own flat and his own body."

In a similar case, soiling the floor was understood to represent the one remaining vestige of control: "I wondered why she would do that and she point blank said it, as plain as day, 'because I can' ... the family were making decisions for her without consulting her." In two others, the message was understood as being a call for attention: "It is self-neglect, but it's kind of attention-seeking in a way; he's kind of caught on that this scares professionals."

Specific disorder

A number of practitioners saw self-neglect that involved hoarding as a disorder in itself, and distinguished it from neglect of self-care, a view that finds some support in the research literature (Frost and Steketee, 2014): "I think there's a real compulsion in hoarding that there isn't in self-neglect [of the person]"; "I think there is a different set of motivations to it". They saw hoarding as having a different psychological presentation: "Something about that sort of mental ability, for want of a better way of describing it, to differentiate between what's important and what's not." Some identified a growing understanding of the role of psychological interventions in addressing hoarding, tapping into motivation from the individual's recognition that part of them does not want to live this way.

6.3.3 Negotiating initial and ongoing engagement

Much of the challenge in self-neglect practice for the practitioners lay in the processes of securing engagement from people who use services, both initially and in the context of ongoing involvement. This section explores the themes emerging from practitioners' accounts, first, in relation to the willingness of people to engage, and second, in relation to the approaches to engagement employed by the practitioners.

The willingness to engage

A number of themes could be identified within the practitioners' accounts of the responses of people who use services to professional interest and concern.

Refusal or withdrawal of permission for access

It was common for access to the home to be refused, often in the early days of contact, but sometimes for much longer, or sporadically: "She regularly wouldn't let you in, she'd lock the door." One service user would go no further than telephone contact. Another would disappear from view, perhaps leaving home for a period of time – "going under the radar a little bit". Sometimes the refusal would be explicit, with the notion of the right to privacy brought in as reinforcement: "No I don't want to see you, I don't want you coming to the property, I'm not going to let you in, what more could you achieve? These are my human rights." Others would have a polite rationale for not meeting, even though they had agreed to the appointment in advance: "She politely explained she would be unable to see me today because ... she had a busy schedule, including buying milk from the corner shop."

Avoidance and deflection

Even if access could be gained, permission to stay was sometimes withdrawn if discussions became too personal: "She was throwing me out quite a lot; you could have a conversation and it would be fine if you talked about the weather." Access may be granted to a small part of the property: "We were only allowed into the back dining room area, which was their living area; she always refused us entry to any other part of the property."

Practitioners could expect strongly argumentative responses at times: "On other days he's up for a good argument and a good fight. He enjoys the drama of a good argument, he sort of provokes it in a way." Anger was another way of closing down conversation when sensitive matters such as personal care were broached, and some practitioners described having felt at risk themselves: "There were occasions I had to leave because he shouted at me or threatened me. Sometimes it felt a bit unsafe with him." Refusal to communicate also signified avoidance: "You could never ever persuade or encourage for her to change her mind, because she would just close her eyes and shut herself off."

Another means of avoidance, or of deflecting attention from a sensitive subject, was reassurance to the practitioner that the matter was in hand: "It's got to be recycled, I'll take it to that bin"; "it's on my to do list". Sometimes the deflection was explicit and direct: "'If you keep mentioning [the clean] and you get the conversation slyly in again', he said 'I'm going to kill myself and leave a note and blame it on you and that will be on your conscience for the rest of your life'."

Rejection of support

Sometimes people were happy for the practitioner to visit and talk, but consistently ignored encouragement to change their ways, and refused any form of practical assistance. This could go on for some time: "I think it took a couple of years ... to get it to that point." Even where services had been agreed and carers were involved in the home, it was not unusual for the carers not to be able to gain entry, or for routine interventions to be refused: "She would decline a carer making her a cup of tea, and we couldn't make out from time to time has she actually eaten." In one case the resident carer would allow cleaning but refused to allow the carers to give his mother any personal care. Rejection sometimes took dramatic forms: "We provided him with a microwave oven and he picked that up and threw it out in the front garden." A further means of rejecting intervention lay in holding out for something that was not likely to be on offer – for example, turning down sheltered or extra-care housing in favour of a 'preferred' solution of a house purchase by the council.

Support was sometimes more readily accepted in certain circumstances than others: "We learned that her pattern was she would always accept help in a crisis, so we knew there was a slightly different pattern of when we could intervene." At times, however, the individual would back track on agreements achieved earlier: "They will ... agree with you, then afterwards they will remove the smoke alarms or get rid of the smoke-retardant bedding." Essentially, many of the more risk-laden behaviours were not seen as up for negotiation, however pleasant the interaction: "He's always smiling because he's a very personable and nice person, but nothing short of a nuclear blast is going to stop him drinking and smoking."

Often no explicit reason was given for rejection of support, but at times practitioners were aware that the person feared more serious interventions if any support was put in place – in effect, a slippery slope of further intrusion:

“He won’t engage [in having someone to go shopping for food], because he probably knows that maybe we’ll put him into a care home for a couple of weeks to make sure he’s okay, because everyone’s so worried about him.”

For others it was thought to be the principle of losing control: “I think that people imagine that the help is going to be overwhelming or controlling or negative.” Money could also be a factor in people refusing services: “She refused to pay; anything involving money is a no-no because ... she wants to save her money for things that are more important to her.”

Acceptance or partial acceptance of some level of support

In a few cases practitioners described a willing and whole-hearted acceptance of support, once it was offered. Sometimes the services agreed to would be minimal monitoring: “He accepted a tiny little bit, just as in monitoring to go round every other day. He might not be in.” But if relationships developed, then further benefits were experienced: “He loved the fact of carers coming round for one hour a day, he really enjoyed that just communicating with the carers.” Sometimes the practitioner’s message seemed to be taken on board with time: “I’ve noticed a little shift in that I think he’s now maybe looking at things thinking, ‘am I really using this, can I do without this?’” Small gains would be made, while other domains of self-care remained resistant to influence:

“The care package was there for the carers to support him with personal care but he wasn’t accepting that part of the care package; he accepted the other part, about the meal preparation, the drinks ... and the cleaning process seemed to stay on top, but we still couldn’t move any further with the hoarding.”

Personal care seemed often to be the most difficult help for people to accept, and this was sometimes attributed to pride: “He was a very proud and private man, so he was not allowing the carers to wash him or dress him or to do anything.”

Unpredictability

Sometimes it was impossible to predict people’s responses, which changed from visit to visit: “If she’s having a good day, we can all go to it and work with her, if she’s having a bad day we can’t even step over her garden boundary.” Visits that start off calmly could change without warning into angry encounters: “She’s quite quickly shrieking at people.”

Practitioners’ approaches to engagement

Professional engagement was approached with a range of different strategies, many uniquely tailored to each individual service user in question.

Building rapport

Practitioners frequently mentioned the importance of forming some kind of personal rapport with the individual. Often this involved overcoming lack of trust left over from previous experiences, and it took time:

“So to have a chance of having any sort of rapport or relationship, trying to achieve everything in two or three visits is just not going to work ... it’s like winning points with someone, until they realise that you’re on their side.”

Sometimes account needed to be taken of gender, with examples given of rapport that was more successfully built by either a male or a female worker. The creation of rapport, even in circumstances where there is no agreement, could be seen as an investment in the future: “I think there’s a lot of situations where ... you can still have a dialogue and at some point, that means that if they have a change, they feel they’re safe to come to you.” Practitioners gave examples of small adjustments they could make to enhance initial rapport, arising from awareness of how they might appear to the person who uses services; these might include removing glasses or badges that were seen as indicative of being in authority, dressing informally and sitting down to minimise any perceived intimidation from being tall. Tuning in to the service user’s potential sense of shame, and refusing to be shocked were similar strategies: “Sometimes saying ‘I’ve seen far worse’ disarms people.” It was a priority to establish some kind of personal connection, some common ground such as shared knowledge of a particular place, or love of music, that was not about the self-neglect: “I like gardening and so we used to go out into the garden and potter around, put a few plants in.”

From rapport to relationship

Building a relationship was a key approach to securing some kind of engagement around the self-neglect, and was central within the practitioners’ narratives about their work: “I think use of relationships is really key.” Relationship was presented as a means to an end, the connection around something unrelated to self-neglect that would in time enable work to be done on the self-neglect: “There isn’t really anything other than just personal relationship that you persuade someone with capacity with to take any actions.” But it was also described as an end in itself: “A lot of it is about relationship building, just that relationship work, that you’re not going to get that far with change but it’s about building a relationship.”

Relationship building in the context of power differentials was sometimes difficult, and involved a hands-off approach to the self-neglect itself: “So it’s quite hard to build a relationship with someone when you feel like you’re telling them what to do.” It was also seen as uncomfortable for the worker, having a strong awareness of risks. But taking time was seen as positive in itself: “I think that’s where you need the time to really unpick what’s happening and not to make a kneejerk response.” Central to relationship building was gaining some understanding of the individual, their interests, their history, and their stories: “Initially talking to her and talking to her about the things she likes doing.” This was seen as a very necessary process, both initially and through ongoing contact:

“Of all the visits probably only 20 per cent of the time we spent with her would probably be trying to have a conversation about her care needs; just by sitting and chatting and looking at her photographs and all of that, I did come to understand her life.”

Personal qualities were also important, best described perhaps as authenticity in the practitioner’s approach: “If you’re genuine and genuinely want to help the person, they can tell I think.” It was described by some as empathy, and by others as

showing a shared humanity: “I cajoled him into soaking his hands in this warm water; I cut his fingernails and do you know, he was so appreciative of that, I really do think, that human touch.”

Vignette: Thomas

Here the practitioner uses the rapport he has built to understand the individual's history and is able to build a future around things that emerge as important; through their relationship he provides companionship and containment at the most difficult points of transition.

Thomas, in his forties, had lived with his mother in a flat that was in a very poor state of repair: very damp, lacking electricity and full of old and broken furniture, which Thomas had long collected from the streets. After his mother's death, he had become very depressed and neglected his own personal care, and the property had deteriorated further. His landlord, however, would not effect any improvements as the whole block was due for major refurbishment and existing tenancies were being terminated.

Liaising with mental health services, the practitioner built rapport with Thomas through attending to practical matters such as benefits. Gradually he got to know and understand Thomas's past, and his relationship with his mother, and helped him to think about what might be a better place to live. Faced with an inevitable move, Thomas was able to come up with a wish list: “better neighbours, less rubbish and shouting, fewer junkies, a quieter road, easy shopping; I'm a loner, I don't need friends.” When the time came to move to the supported living flat they had found, the practitioner helped Thomas to think carefully about what possessions he would need to take with him, unsure whether, when it came to it on the day, Thomas would be able to walk away from the rest. Thomas was, and did; with the practitioner's arm around him he walked away, and while in his new flat he still neglects his self-care, he seems to have left hoarding behind him.

Finding the right tone

There was no one ‘correct’ way of communicating in the self-neglect context. The practitioner's art here was to find the approach to communication that best suited the individual circumstances, and struck the right note, but some key features were suggested. It was important, for example, to give reasons for questions being asked:

“I found I've always gone leaps and bounds by asking questions and explaining why I'm asking it. I find [some] professionals go in and reel off the questions; people clam up. I think it's only fair and common courtesy that people should be given reason as to why such questions are being asked.”

Awareness of how people respond to different modes of communication was important; one practitioner, knowing that sealed envelopes were a source of huge anxiety, sent postcards instead. Sometimes humour and teasing was part of the mix:

“For him it was the ability to be sufficiently friendly and up for teasing; it enabled him to think of you as part of his social network, rather than as a professional and I think you can do that without undermining your professionalism.”

Finding the right balance between honesty (about the state of a property or of the individual's self-care) and non-judgementalism was important, and those who achieved it did so by separating the person from the behaviour, making it possible to express concern about the self-neglect without conveying judgement about the person:

"To be clear that it's because you are concerned and interested about that person, and you are there because you want to prevent harm coming to them. I think that gives you a foot in the door that otherwise you might not get."

One practitioner's overall reflection on the approach of those who had succeeded in engaging people identified a number of key features:

"It's just the way they presented themselves to him; like, you don't go into his flat and look appalled at the state of it, if he wants to sit and talk to you outside for the first few sessions, that's where you chat with him. If he goes off topic and roams, stay with him, just look into his face when you're talking, common sense."

Going at the pace of the individual

Time and patience were seen as key to building and then using relationships to secure change:

"I made the mistake when I first called her, I said, 'I've only got 10 minutes', and she said 'well I suggest you call me back when you've got sufficient time'. And then I realised ... it [needs to be] 90 minutes."

Practitioners were acutely aware that forcing things more quickly than a service user was able to go could risk the loss of even very small levels of engagement: "After three or four attempts in different ways, different dialogues and different words, it got to a point where I thought, 'if I push any more, he's just going to shut me out altogether'." Moving slowly was sometimes a way of building trust, and seeking to empower the person to remain in some degree of control:

"Well please just accept just 15 minutes a week and see if you like it, and you can just say no'. So it's a negotiation; it's about compromise, negotiation and starting really small and building up. Baby steps."

Going back, not walking away, even if it means standing on the doorstep time and time again, was a means of demonstrating care, concern and reliability: "Just to keep going, I'm not going away, we do care, we will keep going until you're okay." Alongside working at the individual's pace was the importance of positive affirmation of small steps that were made.

Having a plan

Sometimes being clear with people who use services about what will happen over a period of time was seen as helpful in creating a sense of containment of a situation, even if the agreed plan is only for a weekly visit, or some other arrangement that creates sufficient engagement to allow assessment and further priorities to be established: "For example, you make an agreement that I'm going to come every week, for an hour, and we'll try this for a month." Such a plan was also helpful in

retaining engagement by being able to remind the person about what had been agreed. With time, such plans can extend to listing more practical, task-focused issues relating to areas of risk that will be addressed over a given period of time.

Finding the motivator

Practitioners were sometimes able to find the one thing that would provide a way through to motivate the service user's engagement. In one case, finding an individual's interest in donating to charity following the death of his wife enabled a hoarded collection to be disposed of in a way the individual found acceptable. Family members could provide opportunity for motivation too: "I said 'if we were to take things out of there with your daughter, would you allow us to remove more things?' and she said, 'fine, yes, take it, I trust my daughter'." For another, it was linking clearing of materials to the valued activity of recycling: "He told me that he recycled, so he had compartmentalised lots of different materials." And for some it was finding a motivation for engagement through recognition of religious belief: "After months of speaking to him every week about God, he finally let me in the house." In order to find the motivator, practitioners needed to have sufficient understanding about the service user's life to be able to identify a key element – an interest, a past experience, a commitment, even a previous employment that resonated with the current situation: "'You worked with people for all those years [as a nurse]; if you saw someone with no food, no drink, would you just walk away?' She laughed and said 'you've got me there'."

Starting with practicalities

One starting point frequently mentioned was the value of providing some practical equipment that could be seen as a positive resource – a new fridge, help to maximise benefits, a repair, a microwave, offered and accepted, was the key to engagement in a number of cases: "They see that you're not there to take things from them, but you are there to give them, and you will carry on working with them." Practitioners found that being seen to have provided some tangible benefit helped with building a positive rapport for further work: "The only times we have managed to make changes is when the worker has managed to build up some kind of alliance over even a small thing and then to build on that."

Focusing on what can be agreed

Practitioners worked to find something that could be the focus of initial agreement, creating consensus that could be built on later: "We've focused on getting a new stair rail ... he's now agreed to have carers do shopping for him ... but he hadn't agreed to any personal care or to any cleaning or clearing up to now." Sometimes this might be the involvement of a volunteer to tackle very specific issues: "He would allow [the volunteer] to go in and read his post, to make sure there weren't red bills; it wasn't a formal package of care ... but the visiting service would be our eyes and ears." The approach was one of "softly, softly" monitoring and supporting by agreement.

Bartering

On occasion the offer of some helpful practicality was linked to some kind of reciprocation from the service user: "If you agree to see the doctor about your memory ... [I can] swap out your bar fire ... for an oil heater, which I can get you for free." Here practitioners would link the provision of a valued resource to something else that the person didn't see as a priority but which could be seen as part of the agreement: "It's about bargaining if you like."

Gentle insistence

Practitioners described trying to seize the moment; sometimes this was to no avail: "Saying 'look, I've got the phone number of a house clearance person, let's ring him now', or 'give me your friend's number, let's phone him now', and he always changes the subject." Others had more success with an occasional assertive intervention at a crucial moment:

"The day that the removal men came, they took her clothes and her mattress and her bed but then I put my arm around her and said, 'come on, let's go' and walked her out of the flat. For some reason, she accepted that and she left the [hoarded] stuff behind and she's left most of that problem behind with her."

Keeping company

Practitioners gave examples of the ways in which they 'kept company' with people they were working with who were doing difficult things, perhaps going along for an interview for involvement in a volunteer project: "So I said to him 'I'll come and knock on your door', they've given us an interview." Others accompanied an individual to a cemetery with flowers for a grave, or to shops. Another form of keeping company was when practitioners gave their work mobile number, so that there was a constantly available link that the person could use if they chose: "I think it's important for the clients to be able to contact you and for them to know that you want to speak to them; you don't want to be on some voicemail where they can't get hold of you."

Encouraging reflection

Reinforcement of the motivator, through feedback from results, was important too, and this related in part to the ability of the individual to reflect on and identify with improvements in their circumstances:

"He was better at defining himself in terms of improvement ... looking at himself and saying, 'look at my environment, it's completely clean; look at me, I don't smell; I've got clean clothes on; I have a carer coming in during the day; the sheltered housing manager keeps telling me how wonderfully I'm doing; I've got friends'."

Thus the positive affirmation and reinforcement mentioned above seeks to reinforce a sense within the service user of valuing the changes made and identifying with improved circumstances.

Straight talking

Practitioners found that straight talking, particularly at a point of crisis, was also an important strategy for securing engagement. This included being honest about the potential consequences of choices that could engage compulsory action: "I've had to be very honest with him, that they will be taking it to court." Straight talking, albeit slowly and carefully delivered, came into its own when motivation faltered:

"We were perhaps a little bit more stick than carrot at that time and we said 'it's part of your tenancy agreement that if your property becomes infested, it affects the other people; we don't want to go

down this road of issuing notice of seeking possession to you, but we will have to do that if you won't allow us to help you'."

Practitioners also engaged in straight talking that would both hear and challenge the perspective of the person who uses services:

"So there was something about literally talking to him as an equal and involving him in the plans and valuing his point of view, even though I often didn't agree with his point of view and I didn't think it was doing him any good, but I'd tell him that."

Such challenges were used also where a practitioner felt the person was not being honest, for example, about drinking, but "I feel like I can do it in a friendly way, so she doesn't feel like I'm judging her."

The power of a uniform

Practitioners recognised that sometimes tangible evidence of authority was useful in securing engagement:

"It may have helped that he had somebody from the fire brigade, who he would perceive as being authoritative, saying 'this and this and this is all a fire hazard', and that would help with his momentum in getting rid of stuff."

Medical staff sometimes held a position of respect that would allow their views to be taken on board: "If you've got a doctor or a nurse there, again they'll take advice a bit more readily I think in that environment."

External levers

There were times when an individual's motivation could be affected by external levers such as threats to tenancy, or the prospect of environmental health action, which could provoke some movement in terms of improving the state of the home: "The motivating factor was he wanted to stay living there and at that point his landlady was saying, 'I want you to stay but you have to keep your flat all right and you have to look after yourself more'." In another case, the potential loss of a tenancy to a property could mean that the individual would no longer be able to care for her dog: "It did win the day for her on it." Coercion alone, however, was not generally advocated; it came into its own when combined with a professional relationship through which a reasoned and empathetic approach could be taken, supporting the individual to continue to make choices within the overall framework of it being necessary to clear material, or allow cleaning to be undertaken.

Vignette: Sylvia

Here the practitioner is prepared to discuss coercive action as part of a supportive relationship; adult social care and environmental health work closely together to provide a framework of authority. They are able to secure a result that preserves Sylvia's independence and provides a longer-term solution over which she exercises a degree of autonomy.

Sylvia's house was overrun with animals, who had free run of her home, with excrement everywhere; some parts of her house were unusable, and Sylvia lived mainly on her sofa in one room, again surrounded by animals. On regular visits from the social worker, which she welcomed provided the conversation was not about the state of her home, she refused to acknowledge there was any problem that needed to be addressed. She believed she had high standards, and to her mind was maintaining them. She was protective of her choice to live as she did, and was assessed as having mental capacity to make that decision.

Environmental health visits, requested by the social worker and undertaken jointly, resulted in her agreeing to make changes, which then did not materialise. Eventually an enforcement order was made. At that point Sylvia brought in and paid for cleaners privately, in order to keep control of the decision and to maintain her independence; she now keeps the state of her home within a tolerance level that, while not free of risk, does not trigger coercive action.

6.3.4 Interventions

A wide range of interventions was used to seek some improvement, or at least to prevent further deterioration, in the self-neglect described by the practitioners. As from the service users' own perspectives, no magic formula emerged, but the practitioners did describe ways of achieving positive benefit of some kind. The processes of intervention were supported and at times determined by two key frameworks – mental capacity and legal mandates – both of which are considered here first, followed by an account of the main forms of intervention that ensued.

Legal mandates

Many practitioners were aware of the existence of legal rules that provided a framework for interventions in self-neglect. The case narratives showed legal literacy in practice:

"We would be regularly exploring the law to make sure that we'd done everything we could around supporting her within her home, and exploring what life would be like if we moved her as well ... we'd hypothesise a lot and then see, based on how we knew her, what impact that would have on her life and would that be worse or better?"

The Mental Health Act 1983 and Mental Capacity Act 2005 were both fore-fronted for consideration, as well as the need for statutory intervention through environmental and public health measures. In a number of cases, removal from home using powers under the National Assistance Act 1948 was actively considered, although in none of the cases was it actually used. Although thresholds legitimising such intervention were reached in some cases, the strong preference was to seek voluntary

engagement: “It’s got to be on their terms and working together.” Coercive powers were seen very much as a last resort.

In some authorities, there was strong evidence of legal interventions being considered between agencies, resulting in a coordinated sequencing of actions:

“The last year we had regular meetings with the public health doctor ... it was so bad because of the infestations that environmental health had to enforce an order so that it was cleaned.”

In others, the welfare and environmental/public health measures appeared to be considered as separate processes, with less overt coordination of intervention.

While statutory powers were routinely considered, there was also recognition of their limitations:

“There are often limits on what you can do from a statutory point of view, so if that’s what you rely on, you might not actually get very far. So it’s better to go in from the welfare concerned approach, because most of the time, you’re reliant on persuading that person to address it rather than forcing them.”

At times, the limitations of legal powers had to be explained to other agencies who assumed that “surely something could be done”: “Actually what we ended up doing was getting solicitors in the meetings to talk about what the limits of the legislation were.”

Mental capacity

In many of the cases described by the practitioners, mental capacity was an issue to be grappled with, and was often the starting point of deciding what could and should be done by way of intervention.

Assumptions of capacity

Many of the practitioners’ narratives demonstrated the ways in which assumptions of capacity were being made, in line with Mental Capacity Act 2005 principles, and there was widespread recognition of the right of individuals with capacity to make unwise decisions. Where enforcement action was envisaged, there was no routine expectation that capacity would be assessed prior to service of the notice.

There were three discernible patterns in practitioners’ engagement with capacity. First, for some, assumption of capacity was made without capacity assessment being carried out. Even ongoing refusal of services in extreme circumstances of self-neglect did not trigger capacity assessment unless there was doubt that the principle of presumption of capacity was misguided.

“There was nothing to really indicate that she had a disturbance or impairment in the functioning of the mind or brain. She appeared to be just ... someone with very strongly held views who didn’t care at all about her impact on others if it got in the way of what she wanted.”

Second, for other practitioners, capacity was the starting point with self-neglect: “One of the first things I would be saying is does this person have capacity to understand the risks and consequences.” Here, it appears that the self-neglect was enough to

put the assumption of capacity into question, and hence capacity needed to be established through assessment at the outset. Finally, capacity assessment was something only to be triggered when engagement could not be achieved; here what was being assessed, in effect, was capacity to refuse services.

Capacity assessment

In cases where mental capacity was questioned, assessment had been undertaken through a variety of channels. Mental health teams were sometimes brought in; in other cases, social workers undertook the capacity assessment, sometimes with an accompanying colleague or a community psychiatric nurse (CPN). GPs were commonly consulted. Reaching a decision could take prolonged dialogue between professionals and repeat visits to the individual:

“The first thing we were looking at was around capacity, does he understand he’s drinking to the excess that it’s life threatening? I went in a few times and felt that he didn’t have capacity, it was quite clear.”

There was evidence of practitioners clearly differentiating between the first and second stages of assessment: “She didn’t meet the initial sort of triggers, she had no mental impairment, so there was no way of moving on to the other four [requirements].” There was clear reasoning on the subtleties embedded in stage two; failure to understand the impact of a health condition, for example, meant that the information couldn’t be ‘weighed and used’; being unable to recall a piece of information a practitioner had given earlier in a conversation indicated inability to retain. There were examples of practitioners finding ways to incorporate practical tasks within the assessment, to explore executive capacity:

“She knew how to put the kettle on, knew how to put the cups out ... she unplugged it all before she poured the water in, she got as far as pouring the water in the cups but she could not work out how to get the teabag in the cup.”

Capacity was also clearly being assessed in relation to specific functions or decisions:

“In some respects he’s got a very high degree of capacity – he goes out and does his shopping, he collects his newspapers ... travels far and wide, but won’t do basic things like throw away his food or store it at the right temperature.”

Thus best interests interventions could be made in relation to specific matters, while the individual retained autonomy over other decisions. This was illustrated in circumstances where out-of-date food would be cleared on the basis of an on-the-spot evaluation by the worker that the individual did not have capacity to exercise judgement in relation to food hygiene.

In cases of uncertainty or of the passage of time, or in changed circumstances, there was evidence of repeat assessments: “So I did a capacity assessment and over the course of the first year three separate professionals did that ... and a psychiatrist also did one as well.” In one case, hospital admission for an acute medical reason, a brain scan revealed historic brain damage that significantly altered the outcome of capacity assessment:

“There was a loss of executive function ... and that actually with hindsight makes perfect sense with everything in her house. She could talk the talk, she could understand, she was very convincing, but when it actually came to it, would she get up and even get herself a glass of water? Extremely rarely.”

In one case the Court of Protection was being asked to determine the level of capacity to manage the flat and to pay heed to food hygiene. And in several cases there was mention of advocacy as a factor in supporting an individual to make a specific decision. There was one instance of an individual without capacity being detained under the DoLS due to explicit unhappiness with the arrangements made for his care, and the need for DoLS was discussed in another case to legitimise a care home placement, although ultimately deemed unnecessary.

Challenges to assessment

Fluctuating capacity was experienced as a challenge by the practitioners, particularly where alcohol was involved: “If you saw him in the morning and then in the afternoon, you’d get very different pictures.” Identifying whether an individual had understanding of all the relevant information was difficult: “Although his comprehension seemed fairly intact ... it was difficult to tell whether he really understood the risks he was putting himself at.” The role of alcohol in impacting on or masking capacity was one that exercised practitioners in many cases: “I think ultimately, if she stopped drinking, the capacity probably would come back, but [because of the risks] we can’t wait until that time.” There were examples of using periods of capacity to make plans with the person for the times when they would not have capacity: “Where capacity is fluctuating, really you can only come up with some sort of crisis plan, and work with him when he has full capacity to come up with a plan of what can we do [when he does not].”

A further challenge was that of identifying whether capacity for small functional decisions denoted capacity to execute an overall self-care strategy:

“I think day-to-day decision making was evident but it’s quite possible that from the decisions and recognising the consequences of decisions, that capacity [to self-care] may have been absent for a while. I must say that isn’t a way we were looking at things, we were looking more at day-to-day decision basis most of the time.”

Differences in professional opinions, in which one agency reached a decision that the individual did not have capacity and another agency concluded that they did, were also a challenge. Hospital admissions by ambulance were a point of such negotiation. In two examples, joint health and social work decisions to undertake best interests admission for life-saving treatment, in the absence of capacity, had been frustrated when the ambulance crew came to a decision that the individual did have capacity to refuse admission, and would not convey them. The outcome left one practitioner reflecting on the challenge of implementing Mental Capacity Act ‘best interests’ decisions, in respect of which there were “so many different points where someone else is a decision maker that it loses its power”, as compared to decisions under the Mental Health Act 1983, which would be implemented without question by those involved in conveying the individual to hospital: “[the Mental

Capacity Act] hasn't got the clean lines of the law within it that the Mental Health Act has."

Capacity assessment threw up in practice the same kind of dilemmas as experienced by practitioners when considering abstract notions of dignity and autonomy. The level of self-neglect in some cases seemed to go beyond their comprehension of behaviour that could be described as 'chosen', on the basis that no person with capacity could possibly choose to live like that, although there was recognition that this would not be sufficient in law:

"If the risks are very high, then it's legitimate sometimes to presume a lack of capacity as a working thesis. [But] you cannot rest there; you have to then exhaustively identify is there a disturbance or impairment."

Some practitioners gave a sense of there being a tipping point, beyond which even capacious refusal must trigger some kind of action:

"How many times can you keep somebody saying no and you can see them in front of your eyes deteriorating, in the same clothes day after day. Or somebody who's barricading themselves in and just opening the door enough for you to see their face, 'sorry, go away, I'm fine', but you can see stacks of papers all the way up and everything falling down."

Others recognised that ongoing capacious refusal would ultimately be respected, and there would come a point when the professional would walk away, but that doing so could not be a quick outcome: "I've kept cases open for a year, two years or more just because [walking away is] not the right thing to do; at least somebody's a point of contact." This view seems to chime with the views of people who use services about the importance of timing, and being able to recognise and take advantage of the right moment. In these kinds of contexts, practitioners sometimes took legal advice on whether all grounds for intervention had indeed been considered: "To make sure that we've really covered all angles."

Outcomes of capacity assessment

Practitioners gave examples of how a decision that an individual did not have capacity led to best interests interventions that could mitigate risk. One person assessed as not having full capacity to handle his finances received support from a charity funded to provide help with handling money, which also contributed to managing other risks in his life:

"He could walk down to their offices three times a week and pick up his money; it was another pair of eyes and ears for us to keep an eye on him and see how he was doing, and notice any deterioration in his health."

Where the outcome of capacity assessment had been a best interests intervention, a wide range of options was considered, and held under constant – weighing the balance between support through a domestic care package (in line with the individual's known wishes to remain at home) and admission to an environment of higher-level care. In one example, where the individual was admitted to a care home, careful work was done to facilitate his capacity to give up the tenancy of his flat, with

positive effects: “I think that helped because it then helped him move on and now he really seems to be settling where he is.”

Removal of an older woman from her son’s neglectful care followed attempts to negotiate and set care targets with him that hadn’t resulted in adequate care:

“I’d already written a letter to the son to explain what we were doing and why, based on the level of risk and the concerns that we had and that he wasn’t able to take that on board. Then we moved her. She went quite well with gentle sort of discussion around it; first of all he wouldn’t have it and it was quite difficult for her to detach from that, but eventually she went and she was quite happy with the move.”

Best interests interventions were sometimes used to secure healthcare in an emergency: “At that point we then said we can’t do anything now, he needs to be in hospital. It’s getting to that stage, and it needs to be under the Mental Capacity Act.”

Vignette: Walter

Here a complex constellation of factors impacted on the provision of services to the individual. Eventually application to the Court of Protection secured the authority to act decisively in his best interests, while enabling him to remain at home.

There were shared concerns between agencies about Walter’s squalid living conditions, which were impacting on the services that were needed to attend to his pressing health needs and to keep him safe. A man in his eighties, he had no means of heating his property, thus risking hypothermia. A constellation of issues had created a vicious circle: nursing services were withdrawn to protect staff, because of infestation from vermin, yet the threshold for enforced action by environmental health was not quite reached. He consistently refused support, but remained at very high risk.

Walter’s case was put to the Court of Protection, which determined that he lacked capacity to make decisions on his self-care and living conditions and granted deputyship, both for welfare and for finance and property. Adult social care services intervened decisively in his best interests; the sequence of interventions included hospitalisation for initial healthcare, and a house clean and clearance in which Walter was present and where practitioners negotiated carefully with him the items that were to be removed. He remains at home, with risks that are more contained; without regular intervention the situation would not be sustainable, but undertaking periodic cleans in his best interests enables Walter to remain in a lifestyle and an environment that are important to him, and which reflect what is known about his wishes.

Forms of intervention

All the examples of interventions that follow arose in situations in which capacity was either assumed or established.

Arrangements that allow monitoring

Sometimes all that could be achieved were low-key interventions to monitor an individual’s wellbeing. These often involved community-based voluntary

organisations providing specific services such as visiting, befriending or support in managing finances:

“He would allow this older visitor from the voluntary agency to go in and read his post, make sure he wasn’t getting red bills; he knew that if his visitor found he was having difficulties or becoming unwell, that he was obliged to tell us.”

Other forms of monitoring involved daily visits to ensure that the temperature in the home was above the minimum set for one particular individual’s wellbeing, checking that it had triggered her son to turn on the heating.

Safe drinking schemes

Sometimes the focus was placed on specific input to mediate risks. To address highly risky levels of alcohol consumption, a safe drinking agreement would, on medical advice, endorse a set amount of alcohol being bought from an individual’s weekly pension, and dispensed by carers at key intervals. The service user, by their own agreement, would not have access independently, the aspiration to remain at home forming the overall motivation for the voluntary restriction:

“He would drink two bottles of wine a day, and no more, and that would keep him on a plateau.”

“... she consented to having carers give her brandy three times a day to a fairly generous measure, but a level that would stop short of the intoxication [of] the past.”

This emphasis on harm reduction rather than elimination of the self-neglecting behaviour was a common theme across practitioners’ accounts.

Fire risk minimisation

A further form of risk mediation related to fire safety. Fire safety checks would frequently be carried out, and as a result fire alarms installed where agreement could be secured: “This was more of a practical, non-procedural way of getting him to work with us, rather than hammer away at all these things that made him cross.”

Sometimes faulty or high-risk heating equipment could be replaced, fire-retardant bedding supplied, and preventive alarm systems installed: “She returned home to a refurbished, cleaned, redecorated flat which had a fire sprinkler system and a care-link alarm linked to the fire brigade in place.”

Adaptations and repairs

Agreement could sometimes be secured to minor adaptations within the home to mitigate risks: “He’s getting a key safe fitted and a care link alarm and a rail on the stairs.” Full physiotherapy assessment could result in numerous improvements to domestic safety and comfort. Even in the absence of overt agreement, interventions sometimes focused on immediate safety: “The next difficulty was getting him to get a door back on his property, and we had two attempts at doing that. The second time we got more police to attend and another couple of social workers.” Sometimes access in order to carry out essential repairs, such as those relating to utilities, was negotiated.

Provision of equipment and furniture

Some homes needed to be made more comfortable where key items of furniture might be absent or were threadbare and needed replacing. White goods were a common offer made to individuals, and in addition to being a form of engagement, as noted earlier, sometimes remained the main form of intervention, focusing on essential equipment for safe storage and preparation of food, such as fridges and microwaves; safe heating equipment, beds and bedding were also commonly provided. Other interventions focused on getting domestic equipment working, or on equipment that would enable the individual to have greater mobility, such as a scooter.

Attention to health concerns

A further practical focus was on ensuring the individual had medical attention to deal with specific health conditions: "It allowed me to then take in the GP to examine him, because there was various things going wrong for him medically that we were worried about." This sometimes involved ensuring that an individual was registered with a GP, or that a psychiatric referral was made; it also involved sometimes accompanying the individual to medical appointments. In some cases the ongoing intervention from community nursing staff became part of the pattern of services being provided.

Emergency respite

When the domestic environment became intolerably squalid, the crisis this provoked sometimes led to the individual agreeing to short-term emergency respite in a care home or other form of supported living:

"She had two cats and one of them passed away, and he'd been in there quite a while and he'd started to decompose. We knew that was a time when we could support her because she was in crisis, so at that time she let us... I think it got to that point where she could hear us at a human level because she needed help."

There were also examples where such an admission resulted in a longer-term supported living arrangement.

Hospital admission

Health concerns sometimes rose to a point where the individual, often with some protracted negotiation, would accept hospital admission for a specific health intervention, which could also result in personal care being provided before a return home. Equally, there were times when life-saving intervention had to be undertaken, where, through necessity, practitioners took responsibility for getting someone to hospital:

"There are cases where we've said to the ambulance service 'actually this is beyond us, you've got to make the call, this person's got to be taken now; if we walk away from here now this person's going to die'."

Sometimes circumstances fulfilled the grounds for admission under the Mental Health Act 1983: "He then went to hospital and he was in hospital for six months and was diagnosed with Korsakoff's type dementia." The individual might return home, but on occasion the hospital admission led to a longer-term supported living

arrangement. There were also examples where people who use services were the subject of guardianship or community treatment orders, and while these were not as a direct input to tackle the self-neglect, they could facilitate a degree of leverage to promote self-care.

Deep cleaning and making safe the domestic environment

Short-term or respite hospital or care admission could be complemented by deep cleaning and modification of the domestic environment prior to an individual's return home. But even without a preceding admission, deep cleaning was a common intervention once the person's agreement had been secured; practitioners recognised, however, that this was unlikely to result in significant change of behaviour, and that over time conditions would again deteriorate, and that even repeat deep cleaning could not achieve significant improvement: "Even with two deep cleans it was still in what I would consider a poor state." Along with cleaning came suggestions for safer and cleaner living – "[I hope] she will agree for the carpet to be changed to slip-resistance cushion flooring" – and sometimes a deep clean triggered some motivation in the person to accept an ongoing care package: "Yes, it's nice, it's clean, I want to keep it clean."

Removal of hoarded material

In some cases the careful work of engagement and negotiation resulted in agreement for some hoarded materials to be removed:

"With his cooperation, we've taken absolutely tons and tons of stuff out of there, it's been a really long process with setbacks where he'll have a crisis and not want us to come in anymore. You just have to give him hours of time and patience."

Hoarded materials were not construed as rubbish, and often needed to be disposed of sensitively, with due regard to their monetary or emotional value: "I asked him what kind of things he was interested in and we identified a few charity shops that he would be willing to donate them to." The understanding of contractors engaged to carry out the work was an essential component of the intervention: "We managed to find a company that were really understanding to his needs and we managed to clear most of the rubbish out the flat." Where repairs were being carried out, practitioners made an agreement with the contractor to focus solely on the single purpose that had been agreed, in order to respect an individual's expectations and control:

"They agreed not to make any comments about the state of the property; they agreed to be in and out in the quickest possible time, and that if they discovered ... any remedial work that needed doing, they would come back and do that another time. Having these parameters that he could cope with, allowed them to go in."

Enabling the person to retain control over the process was seen as important, and could lead to ongoing cooperation with more extensive disposal of materials: "We had a pile that he was able to keep hold of – that was his attachment – and actually, over time, he started to get rid of himself." Strategies of persuasion were oriented to preserving choice and control:

“He wanted to keep his duvet, it kept him warm, it kept him safe and so we said ‘why don’t we get you a new one, keep your old one but maybe put it just in the corner and then swap them around and see what you think with the new one that may keep you warmer at night’ and now he’s got rid of the old one.”

Life management

Support with bills and paperwork was often provided, along with identification of benefits that could be applied for. Sometimes there were specific interventions on matters such as suggesting the making of a will, or making arrangements for valuables.

Care packages

Negotiations with the individual could sometimes secure agreement to services that would support them at home. These included shopping, cleaning, laundry, medication management and personal care, sometimes in combination but sometimes singly; personal care – help with keeping oneself clean, dressing, hair, nails, using the toilet and personal hygiene – was often the last intervention to receive agreement. Sometimes the focus was instead on prompting the individual to undertake essential tasks such as changing clothing and bedding; in other cases food preparation and encouragement to eat were a focus. Meals might be delivered or prepared by carers. Vigilance to prevent pressure sores was important. Sometimes the care package included leisure and social opportunities, with workers accompanying the individual in linking to and using mainstream community services, or to more specialised day care. Here the formation of a strong relationship between the carer and the person using services was key: “I specifically asked the care agency to make it the same carer or two carers ... they did build up a relationship with her”; “she wanted someone that looked like a friend going out; we matched that”.

Actions sometimes needed to be sequenced, with simpler actions preceding more complex ones: “Working with her to clear her paperwork so she then has space to have some cleaning done.” At times, the provision of services had to be negotiated in the context of people being required to make a financial contribution and not being prepared to do so. Some practitioners were able to negotiate fee-waivers with the authorities, but in other cases refusal to pay caused the arrangement to break down.

There were examples of care services that found a strong rapport with people who used their services, and made a key difference in their lives: “They built a rapport and they’ve managed to address some of the issues that then led onto agreement that we could do another blitz and be a bit more proactive on what could actually go as rubbish.” The care agencies involved were crucial to the success of the endeavour, and some were very specialised: “Their carers had backgrounds in mental health, OCD, brain injury.” Practitioners themselves sometimes attended – the presence of someone with whom a relationship had been forged both facilitated access by other workers and enabled the person to retain a sense of control through being drawn into decisions.

Care packages did not always run smoothly and often required ongoing negotiation: “The place is still very dirty ... they’re saying she’s turning away the cleaners and she’s saying that the cleaners are refusing to clean when they come.” Consent was sometimes a tricky issue within the delivery of care packages. Practitioners largely

took the view that consent to an overall package of care was sufficient for the carers to implement that care, but at times this clashed with an approach from carers who took direction from the individual at each step:

“The fridge was just full of mouldy stuff and it was on the support plan to which she had agreed – kitchen hygiene and deal with out-of-date supplies. The carer was asking her whether each item could be thrown out.”

Carers were trained to offer choice and control by asking, for example, whether an individual would like to have the bath that figured on the care plan – asking a yes/no question – whereas the practitioners expected a more persuasive approach: “If I brought a soapy bowl of water to somebody’s feet and [they] without me saying anything put their feet in, I interpret that as consent.” Thus they would expect carers, instead of asking whether the person would like to eat, to cook the food and make it available, or to proceed with a particular care task: “‘Let’s get you dressed’ rather than ‘do you want to get dressed?’” There were times when pursuing detailed consent had potentially serious consequences, as in one example where a carer had asked whether the person wanted any food shopping, and receiving the answer ‘no, I’m fine’ had, without checking the fridge, left the person without food. Practitioners found they often needed to support care agency staff, helping them with understanding the person’s particular needs and finding ways of meeting them in complex circumstances:

“So it was a sort of educational role with the agencies, getting them to understand that ... the drink was part of him, it wasn’t going to change and it would mean that he was more likely to get up, go the bathroom and wash himself in the early stages of the day than later.”

Enforced action

There were examples in which the care that could be provided by consent was insufficient to mitigate the risks, and where enforced action to clear or clean a property had to be taken, using statutory powers held by environmental health. Even then, a careful path had to be trodden, remaining within the legal rules:

“There were a lot of things that were filthy and verminous. We could remove that under one Act, so we spent three days clearing out all of the filthy rotting food and newspapers. But there were also mounds and mounds of [other things] that we couldn’t legally throw out because they weren’t filthy.”

Sometimes the distress of the enforced intervention was evident in the narrative:

“The police attended and had to restrain her, hold her while they got on and did the clean; she was distressed, it was horrendous. All her worldly possessions went in the skip, everything pretty much and it was awful actually, looking back.”

Practitioners often were present when the enforced action was taking place, keeping engagement, supporting and attempting to contain distress: “I went to the cafe with him, sat with him, listened to him and really distracted him while the work was being carried on.”

Statutory action could also enable a range of safety measures to be taken:

“[Environmental health] can bring anyone into the property that is necessary to help enforce the notice. So ... [powers of entry] can be used in a lot of ways to get other services in there.” Environmental health powers could be used to keep other people safe, too, through service of notice on everyone living in a particular property to provide a fire alarm system. Housing departments could also become involved in enforced action, perhaps through issuing eviction notices due to the state of the property, and engaging with structural engineers to identify the risk to weight-bearing capacity as a result of hoarded materials. Such involvement could act as leverage to secure consent for clearing and cleaning to be carried out: “So the client still decided ‘I want to keep that clothing’ or books or whatever, ‘I want that to be recycled or binned’; an hour [at a time] was enough [for him], so [it took] quite a few weeks.”

Therapeutic goals

Some interventions aimed to change the way in which an individual might think about him or herself: “In those situations it’s actually working to have a conceptual shift with the person.” Promoting self-esteem or confidence, or providing alternative patterns of activity within daily living or more positive patterns of social relations, was important: “So it’s not just about that, it’s also about possibly helping him to change the way he thinks about himself.” These less tangible intervention goals were often embedded in practical supports, sometimes in conversations, sometimes in activities. Examples included health activities such as keep fit and swimming, volunteering on parks projects, workshops activities using DIY skills, attendance at lunch clubs and day centres (with additional benefits of providing nourishing food).

Activities sometimes had added significance in the context of hoarding, where they were intended to help mitigate the loss of hoarded material that had been disposed of, filling the void in some way, with something else: “Yes, it’s finding the thing that’s going to be big enough to replace what the person has given up.” There were also examples of practitioners recognising loss and sadness, which were sometimes approached through encouragement to talk about the experiences that gave rise to those feelings. On occasion referral was made for counselling, such as CBT, to address specific issues.

Sometimes underpinning therapeutic work were theoretical perspectives that framed intervention: “The one thing I’ve wondered about recently is whether you could take a sort of motivational interviewing approach to self-neglect.” Maslow’s hierarchy of needs was also cited as a framework for understanding how services might need to be sequenced to meet more fundamental survival needs before motivation for self-actualisation could be engaged.

Vignette: Norma

Here the practitioner uses understanding of the past to recognise what motivates the individual, and creates a plan in which material security provides a foundation for personal aspiration; he provides structure to the helping relationship through being reliable and trustworthy, enabling sometimes tough messages to be conveyed.

Norma is in her late forties, and lives in a hostel. She described herself as never having known her parents, being brought up by anyone in a large extended family who could find space for her – “they let me know that I was sort of an outcast” – and talked about a life lived a life on the streets marked by drink and drugs, sexual abuse, living on hand-outs, keeping company with fellow drinkers, and losing track of time, place and herself. She had all but given up on life when a church outreach project began to offer her meals: “I thought, somebody does care, there are good people round here and if they care I should have more care for myself.”

Giving her some motivation to moderate her use of drugs and alcohol now are physical security, friendship and care from others, counselling, and structured activities that engage her interests and help to give the day some shape. While her self-care has some way to go, it has improved and she has aspirations for her future: “learning about things, anything to keep me sort of satisfied and keep faithful”. Of her social worker she said: “I know when he’s coming here, that gives me something to look forward to, even though sometimes I’m like ‘no, no, not again’, but I know it’s good for me.” Reliability was vital: “if you make an arrangement to meet someone and they don’t turn up, your heart drops like a lead balloon.”

Change of living environment

There were cases in which practitioners had, for different reasons, made arrangements for alternative living accommodation for an individual, enabling them to leave behind a poor environment, perhaps in the private housing sector, harassment and hostility from landlords or neighbours, or an isolated location: “I managed to find him a flat right in the town centre, so then he doesn’t have to walk far to the shops, closer to more amenities.” Often this involved a move to sheltered housing, increasing the amount of support available. In some cases it involved an agreement that hoarded materials would not be moved. Such moves were sometimes negotiated in advance; in some cases they arose from emergency or planned respite arrangements that were then extended in the absence of the person wishing to return home. On occasion, the move was chosen by the individual over their regular living environment, once the opportunity became apparent through experiencing a temporary arrangement:

“He didn’t want to go home ... he really enjoyed being where he was ... it was homely, it had warmth, he had a bed and he would stroke the bed and show us ... it was really quite evident that he was happy; he voted with his feet and he’s now moved into a residential home.”

Complexity in the patterns of intervention

Some case narratives involved a trajectory of interventions in which complex care packages were interspersed with voluntary or compulsory hospital or respite admissions, and where repeat capacity assessment and possibly application to the Court of Protection might ultimately result in a best interests intervention.

Practitioners were tenacious in seeing things through to some kind of resolution, very often acting as the constant thread in the intervention tapestry – negotiating, coordinating, reassuring, containing anxiety from all quarters, acting as a bridge, keeping contact and keeping company. Many gave numerous examples of how they had ‘gone the extra mile’, both within their professional role and in ways that sometimes approached the limits of professional boundaries, driven by very strong expressions of empathy, professional values and personal commitment:

“We do a lot that’s not in our job description ... including personal care, we wouldn’t be human if we didn’t do what naturally came to us and it’s common sense, if you can see an immediate danger, you do your best to resolve that ... so you do what your instincts tell you.”

The emphasis on relationship that was discussed in an earlier section also emerges here in relation to intervention; sometimes the relationship became the intervention: “I would be quite prepared to go on a daily basis and see him, even if he just sat there for an hour and told me that I’d killed him.” Practitioners often knew they would be involved over a long, slow period: “I think it’s about long term, maintaining her health, encouraging her to eat and drink properly and really trying to make the changes subtly but over a long time.”

Interventions involving families and social connections

Sometimes interventions made constructive use of an individual’s family and social connections. Practitioners explicitly sought out the people who might have a way through to the service user through a friendship or some other status:

“Sometimes there are people that they listen to ... [I try to find] what are all the connections here, do they have any historical connections to a church, do they have any connections to a particular sort of culture for example?”

Family members or friends, and in a couple of cases advocates, could sometimes gain access to the person’s home and thus facilitate access by the practitioner: “He had prepared his mother in order to open the door for us, in order to have a discussion and that went well.” The presence of someone else in a household, such as a landlady, could enable better contact to be maintained with an individual, and mitigated some of the risks of self-neglect. Members of community organisations who knew the individual could provide information and insight from their own supportive contact that would be of assistance to the practitioner in gaining an overview of risk and protective factors. Neighbours might be given advice on how to respond in the context of particular demands from the service user. Friends might be asked to keep an eye on an individual who was maintaining a lifestyle that placed them at risk:

“He had homeless people squatting with him, they were his friends.... I from time to time asked them to become his carers ... encouraged them to do certain things to keep him safe ... made sure they got him home safely, if they thought he looked a bit unwell late on, they stayed with him over night, or made sure he had a blanket on when they left him.”

Family members could be instrumental in helping to motivate change:

“His granddaughter had been round to the flat and she’d been in tears – ‘oh you’ve got to get rid of these’. Usually a person’s hoard is stronger than their relationship with their family, but something about his relationship with her made him give us a little window of opportunity.”

In another case, the presence of a trusted daughter facilitated an extensive house cleaning and clearing by consent while individual was in hospital: “Because we’d got a family member involved, we could get a lot more done than if I’d had to do it purely by notice.” Estranged partners were sometimes seen as having the knowledge and trust of the individual, and could work in conjunction with the practitioner, both to provide a fuller picture of circumstances and to effect some change. Sometimes it was possible for a family member to make headway towards a sought goal, at times to impose a solution that could not be imposed by the practitioner: “In the end the daughter said ‘that’s it’; she rang a care company and they’re going in.” In several cases, practitioners and family members worked closely together, the family member taking the lead on clearing and cleaning hoarded and dirty materials that constituted the worst excesses of squalor:

“I would say if I didn’t have the support from the son and his wife, I wouldn’t know how far I would be able to get here. Because of the family’s involvement, because of my rapport with the family, which eventually helped me achieve good rapport/relationship with the client, things could move on.”

Professional intervention could also provoke a shift in family dynamics. In one case, due to the practitioner’s intervention a man and his estranged daughter were able to come together before his death: “We managed to get him to have a meeting with his daughter, which he was absolutely overjoyed about.” In another case there were attempts to facilitate communication between a very ill woman and her sons about matters known to be important to her, such as her wishes about how her death should be dealt with. Stressors for a daughter with mental health problems caring for her self-neglectful mother were mitigated when the practitioner was able to secure the mother’s agreement to accept help in the home.

Not all family and social network involvements were experienced as positive in the context of intervention goals, with examples of family influence working against and reversing what had been decided: “It’s when the son comes back and says ‘you don’t want to do that, mum, you don’t want to go and meet those people’, it undoes several months of work in one sentence.” In other cases family members were seen as complicit in maintaining the person’s self-neglect – albeit supporting them in practical terms – or as ignoring the issue completely:

“The son was visiting every weekend and he didn’t notice his mum’s urine and faecal incontinence, that she was losing a massive amount of weight; he knew there were empty tin cans in the cupboard but there was absolutely no food.”

Practitioners were often exercised by co-dependencies within a self-neglect situation, recognising that changes achieved in relation to one person’s care, whether by negotiation and agreement or by best interests intervention in the absence of capacity, could have implications for another:

“It brought up the impact of neglect in a family, so you can change one person’s life but it might make another person’s life extremely poor because of that, because of the dependency they have on each other.”

6.3.5 Working within the organisational context

Practitioners commented on aspects of their team and organisational context that had either helped or hindered self-neglect practice. They foregrounded in particular the extent to which established organisational expectations about workflow could accommodate and adapt to the particular requirements of practice in self-neglect cases.

Care management

The primary observation was that self-neglect practice, because of its reliance on building relationships and engaging in long, slow negotiations, does not fit with organisational expectations on timescales, either for the amount of time allocated to any one case or for the length of time a case would remain open. These expectations were seen as derived from care management models that assumed a neat and predictable relationship between assessment, service provision and closure, and did not rely on longer-term engagement:

“These clients don’t fit into care management, it’s not a case of here’s a referral, open the case, go in, put a care package, close the case ... it doesn’t work, it’s about building rapport, it’s proper social work.”

Practitioners experienced pressure to close cases prematurely, in terms of the work being done, where they had been involved beyond a certain time point without securing a ‘result’. Sometimes they absorbed the time demand without adjustment elsewhere in their workload:

“One very practical impact is that it’s massively time-consuming and that’s not a problem caused by the client’s situation, it’s caused by less and less time to do direct work ... where I’m out trying to see [someone] three times a week for a short time, the knock-on effect on me is incredible.”

In some agencies cases could be placed on an intermediate status – “You are sort of ... ‘encouraged’ for want of a better word, to make sure you put people on review rather than keeping them open” – in which review would take place after a period of inactivity, but this, too, was seen as inappropriate in the context of self-neglect where greater continuity of involvement was required. Self-neglect was not always accessible to standard assessment within a care management model, and that it needed to be conducted over a period of time, as trust was built.

Self-neglect practice was often likened to ‘real social work’ – an observation made most frequently by social workers themselves: “If somebody’s self-neglecting, they may well need time to build the relationship in the first place and that’s the more traditional social work role, as opposed to the care management role.” There was a view that care management had become too dominant a part of social work practice. Practitioners sometimes commented on the need to resist premature case closure and to stand up for their professional view that further ongoing work was required: “I think it’s about having the confidence in your own profession and being able to do that”; “you’ve got to give the staff time to work with these clients”. They understood the management pressures of performance targets and indicators, but were concerned at what was sometimes seen as a lack of recognition from managers of what was involved in good self-neglect practice:

“I don’t think our managers know all the extra miles that we always go ... all they see is how many assessments have you done in a six-month period.”

“... if people knew what you did, we would be hung, drawn and quartered.”

Practitioners felt there was a need to develop a monitoring and preventive culture around self-neglect, which would incorporate the expectation that staff would have space to research and try approaches rather than applying formulaic solutions within a time-limited model.

Such pressures, however, were not universally experienced. Some practitioners commented on the level of trust placed in them: “Increasingly here there’s a trend to trust in the social worker’s, the practitioner’s, judgement.” Practitioners who were not in care management roles were able to engage over longer periods: “I suppose the luxury with our job is sometimes we have that little bit longer to try and get people to engage, over a longer period of time than maybe what a social worker could.” Service models in which social work and outreach work were incorporated within team structures, rather than being organised as separate services, were thought to facilitate proactive, time-rich engagement through ease of communication and transfer between workers.

Thresholds

Rising eligibility thresholds in adult social care were seen as problematic, in that they determined whether a response is made: “You’ve got obviously the FACS criteria, so how [self-neglect] sits in the FACS criteria, I think that’s part of the problem.” Eligibility criteria could militate against becoming involved in a preventive role, either when a self-neglect situation first came to light, or at a point when intervention might be more easily negotiated, before behaviour became entrenched. Where the risks in a situation had not reached the level of either ‘critical’ or ‘substantial’, then pre-emptive involvement could be difficult to achieve. Equally, where risks had been reduced through a crisis response, ongoing involvement could be subject to eligibility scrutiny, adding to pressure to close the case rather than invest time in an ongoing relationship.

Interface between safeguarding and self-neglect practice

One organisational debate within adult social care is whether self-neglect is dealt with under safeguarding or within care management, and there were examples of both in the present study.

“People who may be self-neglecting and there’s not an actual perpetrator of abuse, may come in a different way through our helpdesk, therefore will be flagged up as a social work/care management assessment rather than adult protection/safeguarding.”

It was not uncommon, even where safeguarding structures had taken an overview of self-neglect, for it to remain within the broader remit of adult social care teams:

“Although it comes under the remit of safeguarding, we don’t look at it under adult protection as such; we expect the social workers, the care managers, to support the people who are self-neglecting as opposed to it being adult protection.”

Safeguarding procedures, however, were seen as providing additional leverage to secure engagement from other agencies: “At least under safeguarding, then there’s some leverage to say, ‘this comes under safeguarding policy so therefore you need to be addressing this’.” Equally, they were perceived as offering a means of review and accountability through SCR when things go wrong, whereas outside of safeguarding the review process is less clear: “The fact there’s no mechanism is slightly embarrassing for the council ... that’s going to be taken up with our Adult Safeguarding Board.”

6.3.6 Working with others

Intervention in cases of self-neglect, while often led or coordinated by adult social care, typically engaged multi-agency involvement, and working with others outside the immediate team environment became an imperative. Practitioners gave many examples of ways in which inter-professional working was structured into their work. Sometimes inter-professional and inter-agency practice evolved as a result of multiple parallel strands of involvement; sometimes it was created through an explicit strategy. GPs were frequently involved; others often mentioned were district nurses, community matrons, psychiatrists and community nurses from mental health services, drug and alcohol services, psychologists, physiotherapists and occupational therapists, community chiropody and dentistry, pharmacy, community physicians, ambulance crew, housing, environmental health, fire services, the police, social landlords, voluntary organisations, solicitors, advocates, welfare benefits, animal welfare, all as necessitated by the particular presentation of the individual concerned. The difference between children’s and adults’ services was noted; in the former, inter-agency practice is regulated (by statutory guidance), whereas in the latter “it’s happening but there’s less emphasis on procedures”.

There were a number of dynamics that affected the extent to which inter-professional and inter-agency work was a constructive feature of self-neglect practice.

Ownership

The all-pervading nature of self-neglect work raised problems of ownership; if everyone does it, then determining who holds responsibility can be difficult. Service boundaries could be seen as barriers to securing input. “We get ‘It doesn’t fit into our

team'; but it's about crossing those boundaries and about the department recognising that, which doesn't actually happen." Both funding responsibility and diagnosis could be determining factors, with personality disorder and learning disability both potentially being excluded from specialist services: "Personality disorders don't fit anywhere so we tend to take [them] and learning disabilities that are on the cusp as well." Other specialist teams were seen as having eligibility criteria that often people who self-neglect did not meet: "The drug and alcohol team, they'll only work with people if they want to stop drinking and I think if they want to stop drinking, the hard part's done." There were also difficulties securing mental health involvement for people who did not have a diagnosis and who would not easily engage with assessment, unless a crisis response such as assessment for hospital admission under the Mental Health Act was called for: "They tend to deal with acute episodes and acute problems, they don't really want to engage longer-term and that was the frustration because I felt that was the way forward." Conversely, a mental health team that would take referrals openly and provide advice or support was much valued by practitioners in one authority. Others felt that it was all very much left to adult social care, giving examples of difficulty engaging even GPs in situations of severe concern about health: "I've invited all the agencies that are involved and nobody wants to come or they can't make it ... it's impossible. I've never had a GP ever come to a meeting."

Integrated teams, or teams operating integrated care pathways, were seen as bringing benefits of shared ownership, with different services taking a lead at different points in the pathway. There were also benefits from the broadening of eligibility:

"Within the FACS criteria, we've worked with substantial and critical people within the social work part of our team; our community nurses tend to work with the other people, they're not concerned about eligibility in that respect ... so as a team we work with everyone whether they've got low needs, no needs or critical needs."

Integration was seen as bringing other benefits of access to information: "We don't have that much communication problems and because we are on the health side, we can also see their notes in the system, so communication is not a major issue."

Shifting organisational priorities

Sometimes the equilibrium of self-neglect services could be disrupted by changes within one part of the system – changing service patterns within one agency – with knock-on effects for others. In one authority, changes to policing meant that the community policing practice of keeping an eye on people living in 'risky' situations could no longer be easily fulfilled:

"They were probably one of the huge contributory factors to dealing with self-neglect, even the people that don't want to engage, because often people will engage if someone's in a uniform. It's the old school 'hello, just come to see how you are'."

In another example, joint funding of a post to engage with the housing situation of people with mental health problems had had to be withdrawn.

Clarity on roles and relationships

There were many examples in which, despite the challenges noted above, self-neglect work was very well coordinated, roles were clear and goals were well understood: “We’d structure it around all of our professional identified roles, so why were we there, what was our role within supporting this woman?” District nursing would be attending to health needs relating to an underlying medical condition; carers would be ensuring the individual had eaten and helping to keep the living accommodation relatively clear and clean; the social worker would take a coordinating role and negotiate with the individual, keeping an overview of the legal mandates being used and considering options as circumstances changed. Such clarity, however, was not always achieved: “Some health professionals think that social services are about giving out money and food.”

However, roles were not necessarily adhered to rigidly. There were examples where creative use was made of differing levels of acceptance of different professional groups, involving a degree of role blurring, particularly to secure engagement:

“I offered all of the usual things, he wouldn’t accept help so the GP said ‘I can go back out, I need to do a general health check, do the flu jab ... let’s try and build up a rapport, gain access and get clear understanding of capacity’.”

Emphasis was placed on finding the right person to make the initial approach. Fire services’ involvement, for example, was recognised as being sometimes more acceptable, and thus provided a bridge to the involvement of other agencies.

Shared understanding and goals

There were sometimes challenges in coordinating the efforts of different services to ensure that all were working from shared understandings and goals. Different capacity assessment outcomes, mentioned earlier in the context of hospital admission by ambulance, have been shown to be problematic in terms of services moving together towards shared goals. Equally, frustrations about the timing of visits arose: “They used to send the district nurse to do blood monitoring on an afternoon, which was when she would go to bed ... changing it ‘wouldn’t fit in with rotas’.”

Different positions between services on key issues were commented on. Social workers were thought to sometimes delay intervention decisions, perhaps being more reluctant than other agencies to engage in coercive action:

“They said ‘we need to remove her, we’re colluding with the neglect’, whereas we were working from a social work perspective saying she’s clearly expressed how she wants to live, she still has some capacity to say what she wants ... we need to work with it and plan.”

The pressure from other agencies to initiate protective action was sometimes experienced as extreme: “I think they’d put the whole of England in care sometimes.” Equally, there was a tendency for some services to over-estimate what others could do in terms of intervention, and what mandates existed. Thresholds for concern could also differ: “They think ‘we don’t know what to do with her, let’s put a referral in and say self-neglect’.” There were also examples of single agencies pursuing their own agenda without strong tie-in with an overall plan or direction: “They’ve had

enough and they're ready to go to court, they're ready to throw all forms of legislation at them."

Conversely, there were many examples of strong inter-agency working to secure key goals: "We went with the police and they were fantastic ... very supportive. We had a discussion outside about which legislation we were using." It was common for joint visits to be made by social workers and nurses. Adult social care staff attended regular GP surgery meetings. Giving a consistent message to the individual was very beneficial when it could be achieved:

"I think because everybody involved is working as a unit and we're all consistent about what we're saying to this lady, then we're all trying to get her to understand we're trying to give her a better life for her daily living."

Where coercive action was to be taken, pre-planning by those involved – social worker, outreach worker, environmental health, police – enabled shared plans and contingency arrangements to be put in place: "And then on the day, we were all there and we all knew what our roles were." Discussion at the inter-agency risk panels or networks mentioned earlier could result in a better level of shared understanding of what could or should be done, and of the priorities for moving forward in a specific case:

"It's about knowing what statutory powers other services have got, or what other non-statutory interventions they can make; people found that really helpful to understand what the abilities and limits of other services were."

Formalising discussion in such a meeting was also useful as a means of bringing in services that might have been reluctant to become involved previously.

Communication and information sharing

While inter-agency communication and information sharing were emphasised as important, experience of these in practice was mixed: "Almost the challenge is not to manage his needs but to manage the multi-agency process and get some professionals to share information." In one case, inadequate information at the point of referral resulted in a non-urgent response being made, in circumstances that would have warranted more urgent attention. In another, lack of communication about a case history contributed to a failure on the part of several services to maintain contact, with the individual finally discovered in a state of extreme neglect, which resulted in their death. Adult social care practitioners located in multi-disciplinary teams or within integrated pathways found access to information, and indeed to informal communications with other professions, easier to achieve: "The intervention and the understanding is the same, but I think you feel more on your own in a community team than in a mental health team."

6.3.7 Outcomes of self-neglect practice

Self-neglect practice resulted in a range of outcomes. There was much that was positive; sometimes outcomes were more mixed, and there were disappointments too.

Positive impacts on health and wellbeing

In many cases practitioners could point to positive differences in the lives of people who use services. Clear improvements were noted to basic comforts, physical and mental health and overall wellbeing. This practitioner described a fairly typical picture:

“Just through things like a good diet, food, drink, stimulation and warmth and things like that – those basic levels we were talking about – his mental health and his wellbeing did improve. His health really did improve.”

These benefits were sometimes achieved as a result of a move to different living accommodation. Service users who, by whatever route, had ended up in care homes were seen to be settled and content, experiencing the physical and emotional benefits of better personal care, as well as a greater level of sociability. In other sheltered environments, similar outcomes were observed, with a particular emphasis in some cases on not merely making someone safe, but making it possible for them to retain an element of their independent lifestyle:

“He really seems to be settling where he is, because they allow his behaviour, so he sleeps out a lot in the garden on the bench and he’s allowed to barricade his room if he wants to. They’ve respected his personality and his lifestyle but just the risks are reduced.”

Similar positive outcomes were also experienced in the context of domestic environments, as a result of care packages that were effective:

“She just needed some TLC. She was getting regular meals and her medication seemed to be working and her skin improved. She was getting clean clothes, getting a wash ... we got her to the point where she felt she wanted to start going out, so we got her some day care. She met other people and she’s quite a happy lady now.”

The social benefits of company, which acted also as a motivator for self-care, were often noted. Improvements were made to domestic environments too with resultant benefits for safety and security: “The client’s environment is a lot safer and her tenancy’s being maintained.” There were examples in which people enjoyed the social companionship of having carers in their home; sometimes they also developed pride in their surroundings, and took steps to continue the improvements made. Positive changes were also noted in their emotional wellbeing: “We’ve all noticed a happier man over the last year.”

Better personal care, diet and closer involvement with health services also resulted in greater stability and reduced risk from health conditions, such as diabetes, through more regular medication. In some cases the outcome noted constituted small steps on a longer trajectory:

“We know that he’s getting cooked meals, he’s getting the bus and he showers ... and he’s starting to come out of his shell a lot more as well by engaging in the services. So we’ve got the evidence to show that quality of life could be better but it’s a really slow, slow process.”

The positive outcomes were a source of professional pride for practitioners: “I would class this work as one of the most successful pieces of work I have ever undertaken, during my years in social work.”

Vignette: Arthur

Here there is multi-disciplinary involvement and close collaboration between health and social care in undertaking a capacity assessment that considers executive function. The outcome allows risks to be managed while enabling the individual to continue to live at home.

Arthur, in his seventies, was an alcoholic whose drinking had spiralled out of control. He was also a heavy smoker, and spent his days and often nights too in an armchair, which was surrounded by accumulated papers and debris. Fire risks were extreme and, following a fire risk assessment, alarms had been installed. His self-care, however, continued to deteriorate, and although he agreed to carers being involved to keep the state of his accommodation relatively clean, he would not allow them to offer personal care. He always promised to eat the food they prepared, but didn't; he was losing weight, and his skin was deteriorating badly. Occasionally he would agree to change his clothes, which were always very dirty due to his incontinence, but didn't carry this through. It was understood by those involved in his care that he had mental capacity to decide on his daily care arrangements and that any interventions could only take place with his explicit agreement.

When Arthur was admitted to hospital for treatment after a fall, practitioners suggested that significantly more in-depth investigation of capacity was warranted, given Arthur's long history of not following through on declared intent. Cognitive testing and brain scans were carried out, and established that he did indeed have historic brain damage dating most probably from a road traffic accident many years previously. This led to a finding that he had some loss of executive function, interfering with his capacity to undertake self-care, and opened up the potential that future care plans could incorporate interventions in his best interests. Arthur did return home, in line with his wishes, but with a considerably enhanced and more assertive care package that sought to control his drinking, further contain fire risks, and maintain his personal care.

Mixed outcomes

The outcomes were not always what practitioners would have wished for, although it was rare for there to be no positive change, however small. Often key to defining the positive element was the recognition that damage had been limited, rather than lifelong behaviour or core life position changed: “We can't change some things for him; we can't bring his parents back, we can't fundamentally change his comprehension of the world.” Perhaps one room had been cleared and was being used for its intended purpose, even though hoarded material had been moved to other rooms. Thus practitioners sometimes had to settle for less than ideal resolution: “We got to the point where that was as good as it was going to get really.” Sometimes what had been achieved was removal of immediate risk, and perhaps the creation of a relationship that could be re-activated should things deteriorate in the future. Sometimes, in the meantime, a series of community-based eyes and ears

had been put in place discretely to monitor wellbeing, or a family involvement activated.

There was a sense of regret at opportunities missed when people remained implacable in their refusal. Often practitioners would have wished to reduce risks further, either by carrying out adaptations of the environment or by securing stronger motivation for behaviour change, or indeed by effecting a move to a care environment. But there was often recognition that this would mean going beyond what the person could envisage:

“We weren’t able to have a breakthrough on the personal care, but we ensured that he wasn’t going to freeze, he wasn’t going to die in a fire and ... it would fit all the social work theories around meaningful engagement and empowerment, keeping true to the person.”

In some cases there was a feeling that society’s expectations may be set too high, and that small achievements needed to be recognised: “Going into his home, you’d think ‘what are social services doing for him?’ but actually for him it works really well.... Is he safe? Yes. Is he eating and drinking? Yes, and he has carers going in every day.” In a number of cases it was clear that practitioners saw remaining true to an individual’s core aspiration to retain autonomy as a significant outcome in itself: “I think somehow we’re able to maintain or respect her wish ... to be in her own home and be able to make day-to-day choice about how she lived, which we achieved to the end really.”

Sometimes there were costs to improvements in living conditions that had been achieved through extreme reluctance on the part of the individual concerned, or which were the result of coercive action. Immediate relief to risk had been achieved, but had caused distress, anger and a sense of loss, and were often without long-lasting impact on an individual’s lifestyle choices.

In a number of cases, the long-term outcome was not yet known, as, for example, in cases of admission to hospital under the Mental Health Act, where either treatment was ongoing or long-term rehabilitation was in hand in a protected environment. Sometimes a person died before resolution of the self-neglect could be achieved.

Doing things differently

Sometimes when outcomes were mixed, or resolution of the self-neglect wasn’t fully achieved, practitioners reflected on things they wished they had done, not necessarily things that would have changed the outcome, but adjustments that could have meant something to the person’s known wishes and feelings:

“If I could go back and do it again, I would have facilitated her return home quicker. She wasn’t medically fit but I think if I’d have got the doctors and said ‘look, this lady, we know she’s dying, she wants to die at home’.”

Other reflections were more general in terms of approaches that would have been useful but were not easily available in the current service context; specialist psychiatric or psychological support to tackle the hoarding came into this category. There was a perceived danger that services would neglect a person who was known to be self-neglecting and to be resistant to support: “She was an alcoholic, she did smoke and drink but she still needed that help.”

6.3.8 Practitioners' wisdom

Practitioners were asked what wisdom they would pass on from their experience of making a difference in self-neglect practice. The following comments summarise the approach they advocate, about which there was a large measure of consensus.

- Place concern for the individual's wellbeing at the forefront of your approach, rather than any judgement about standards or exercise of authority.
- Make sure you understand their level of capacity to make key decisions.
- Prioritise building rapport, and work for a relationship in which trust can become a key feature; keep going back, don't walk away.
- Be interested in the person and their life story, and why they're living as they are.
- Have a vision about how things could be different, and stay hopeful, but pace the goals and keep them realistic.
- Be led by people about where they wanted to start, but then establish some rules about how you're going to help them. Find a balance between working at their pace and giving them a push forward.
- Be open, transparent, honest, persistent, patient.
- Involve others with specialist expertise to help assess and meet the individual's needs.
- Recognise it will take time for someone to accept different kinds of support, and for changes to be made.
- Find carers who can show empathy, tolerance and persuasion, and with whom the individual will be comfortable.
- Have all the agencies working to the same goals and coordinated plan.
- Mobilise family members both to contribute to and to support the plan.
- Use community resources to connect people to activities that support their wellbeing.
- Be prepared to challenge others if necessary.
- Be clear about your legal mandates and options.
- Negotiate the time and space to do the work.
- Use personal and professional support mechanisms.

Time and relationship were the key features, bringing a re-connection with a valued professional orientation for those who had a social work background:

"You've got to recognise that it's a long-term work, it doesn't happen overnight, it is about working with the client, you will get frustrated."

“It’s really uncomfortable sometimes with the fact that somebody could be living in an environment where they’re at risk. But use of relationships is really key.”

“It’s proper, old-fashioned social work.”

Other practitioners, too, beyond those who were social work-qualified, espoused this approach, key to which seemed to be an integration of personal and professional qualities encapsulated perhaps in what service users themselves, when describing those practitioners who had enabled them to make a difference to their lives, called ‘being human’.

7. Conclusion

This research set out to identify what could be learned from policies and practices that have produced positive outcomes in self-neglect, from the perspectives of three key groups of stakeholders in such work – managers, practitioners and people who use services. These concluding comments summarise and synthesise some of the key findings at the levels both of strategic infrastructure and of daily practice.

7.1 Creating an infrastructure for self-neglect practice

7.1.1 Strategic responses to self-neglect

LSABs and local authorities have adopted different approaches to the location of strategic responsibility for self-neglect. Some have excluded self-neglect from their policy development and scrutiny remit. Others, and the survey would suggest around two-thirds, have conversely located self-neglect squarely within their mandate, developing protocols and policies on hoarding, referrals pathways, capacity assessments and risk management, for instance, and using SCRs, lessons learned reviews and individual agency reviews to develop practice guidance. Yet others have overseen the development of a model of panels, to which cases of self-neglect involving adults at risk can be referred, the operation of which is then left to the local authority and its partners. Strategically, the development of policies, protocols and practice tools to meet the challenges posed by cases of self-neglect needs an organisational home. Given that no one agency has all the knowledge or skills to tackle these challenges, and given that LSABs are one forum in which all agencies with roles, powers and duties with respect to adult safeguarding and the care, wellbeing and protection of adults at risk, come together, they offer just such an organisational home.

LSABs can establish the strategic commitments, reflected in policies and protocols concerning the management of risk, needs and capacity assessments, for example, which statutory and third sector organisations will implement in cases of self-neglect. LSABs can coordinate multi-agency training and adopt approaches to learning and service development that disseminate good practice. They can configure referral pathways and promote the development of panels and multi-disciplinary forums at which complex cases can be presented for discussion and action planning. Indeed, managers who completed the survey and who were interviewed expressed confidence in the mechanisms for inter-agency collaboration, coupled with referral pathways, which had been developed under the auspices of the LSAB. Moreover, a sense emerged from both the manager and practitioner interviews that policy initiatives, for example, with respect to multi-agency practice, might be more effective than training in ensuring that the strategic intent in agreements across professional groups and agencies is effectively operationalised in practice.

7.1.2 Data collection

Currently no accurate data exists for the prevalence of self-neglect. The majority of local authorities did not collect data on self-neglect, and this limits policy development and practice learning in an area where frontline practitioners and their managers highlight anxiety and concern. Where local authorities provided estimates of the percentage of self-neglect scenarios within total caseloads, they were not confident in their accuracy. Very few local authorities collected outcome data. However, as some managers commented, both in their survey responses and in

interviews, it would be relatively easy to record instances of self-neglect and practice outcomes. Collecting such data locally and nationally would enable quantification of the size of the challenge that self-neglect cases pose to local authorities and their statutory partners. Scrutiny of outcome data would add to the evidence base that has been presented in this report for effective practice with adults who self-neglect. Of course certain challenges would need to be overcome before data collection could be robust, notably, the variation in definitions of self-neglect and the thresholds that might apply, but this is certainly a surmountable obstacle that has been addressed elsewhere (for example, in the US).

7.1.3 Defining self-neglect

Just over half of the local authorities that responded to the survey had defined self-neglect in their guidance or protocols. There remains, however, some diversity of understanding: for example, some managers and practitioners defined self-neglect as comprising those situations where adults with capacity place themselves or other people at significant risk of harm; others included both adults with and without capacity in their definition. Moving towards a national definition of self-neglect might be helpful, and there was some evidence, here and elsewhere, that previous research on scoping self-neglect (Braye *et al*, 2011a) had been used as the basis for exploring the parameters of policy and practice. Self-neglect for definitional purposes then includes both adults with and without capacity, and centres on:

- lack of self-care – neglect of personal hygiene, nutrition, hydration, and/or health, thereby endangering safety and wellbeing, and/or
- lack of care of one's environment – squalor and hoarding, in the context of
- refusal of services that would mitigate risk of harm.

7.1.4 Training

Just under half of the local authorities that completed the survey did not provide specific training on self-neglect. Practitioners and managers reported that they were more likely to have briefly touched on self-neglect in training that had another principal objective, such as providing knowledge or skills relating to mental capacity assessments. Yet work with adults who self-neglect was often described as an uncomfortable place. Various, practitioners especially felt exposed and isolated, coping with repeated disappointments and frustrations, anxious about whether they would be blamed, distressed and moved by the circumstances they witnessed, emotionally exhausted and conflicted about how to balance a duty of care with a person's right to private life and autonomy. Perhaps it is no surprise, therefore, that managers and practitioners have been keen to learn about what is effective in organisational and practice terms for working with cases of self-neglect, and that earlier research on self-neglect (Braye *et al*, 2011a, 2013) has been widely used. The evidence suggests that more attention should be paid in training and practice development to the ethical challenges, legal options and skills involved in working with adults who self-neglect.

7.2 Effective self-neglect practice

7.2.1 Relationships built over time

Across the managers, practitioners and people who use services who were interviewed, the importance of relationship-based and person-centred practice was emphasised. For some managers and practitioners, in particular, this was accompanied with the observation that self-neglect work demanded highly skilled and resilient practice that therefore required thoughtful allocation decisions. Practitioners and people who use services talked about the importance of taking time, being genuine and human, demonstrating empathy and care, judging pace and when to be hands-on and when hands-off, and finding out about the individual. Trust needed to be established, subsequent to which encouragement could be mixed with concerned curiosity and, when necessary, honesty-based authority and direction; non-judgementalism did not mean silence on risks and concerns. All were agreed that responses had to be flexible due to the variety of situations and dispositions that might be encapsulated within the term 'self-neglect'. Many were also agreed that care management systems did not promote effective practice with adults who self-neglect where they restricted the time and focus of the practitioner.

7.2.2 Finding the person

Person-centred practice meant looking at the whole person rather than just that part that might fit into an organisation's specific remit. It meant searching for this particular individual's experience, both of involvement with health and social care agencies, and of historical life events such as childhood, trauma, loss and relationships. It meant following through a process of seeking to engage, once this had begun, rather than terminating involvement, since this could miss opportunities to respond to moments of motivation. It meant understanding what might lie behind unwillingness to engage, which could include shame and embarrassment, fear and anxiety, lack of knowledge about options from services, and views about acceptable input. It meant recognising that neglect of self-care and/or of one's environment could be the result of inability, disinterest, past influences and/or the attribution of value to particular possessions. Person-centred and relationship-based practice would also involve recognition that self-neglect might provoke stress, anxiety and shame, but so too might the interventions designed to improve the recipient's wellbeing. It would involve finding a bespoke intervention, or set of interventions, given the different manifestations and causes of self-neglect. This approach to practice has to be held in mind by operational and strategic managers if it is to be sustained by practitioners.

7.2.3 Mental capacity and legal literacy

Effective practice also required an in-depth understanding of the Mental Capacity Act 2005. Here, previous research (Braye *et al*, 2011a) had been influential for some practitioners and managers by directing attention to executive capacity as well as decisional capacity. Capacity is a key determinant of what can and should take place by way of intervention. It was clear that in many cases, capacity was being evaluated with a fine-tuned approach, seeking to identify in what, if any, domains of an individual's life best interests interventions should be made, and to judge the scope of that intervention, respecting autonomy in relation to matters for which capacity remained. Nonetheless, the thoroughness with which capacity assessments are completed and reviewed remains a concern.

Alongside knowledge of, and skills in, assessing mental capacity is knowledge of the different options that law may offer, and skills in navigating through the meaning of, and interfaces between, different legal rules. Once again, the importance of access to specialist advice becomes important, as does accurate knowledge of the range of options, and supervision that offers time to reflect. Not infrequently, practitioners and managers commented on the challenge presented by those with capacity who present significant risks to themselves and others. Different legal routes may offer one set of options here, and indeed, options that must be at least considered (if only to be ruled out) if a breach of statutory duty is not to occur.

7.2.4 Flexible interventions

There was no clear 'ideal type' intervention in self-neglect, and no substitute for personalised approaches. What mattered to practitioners was finding out what mattered to the individual, and, informed by an understanding of that, moving things on within the service user's zone of tolerance. Such an approach was also valued in the service users' narratives. There was a sense that interventions needed to be staged, attending first to basic needs of practical safety, food, and security of the home before being able to engage with work on care of the domestic environment, then personal care and finally, perhaps, work towards activities, social relations, self-esteem and confidence. Practitioners in particular were circumspect about goals, recognising that with consent they would probably only travel part of the way that could ideally be envisaged, although the willingness to go the extra mile was very evident in many accounts. One way of pushing the boundaries was to continue to 'be present' for the service user, keeping company through difficult periods or tasks, helping to contain anxiety and distress. Some practitioners realised that if they were asking an individual to give something up, whether a collection of hoarded materials or an established lifestyle pattern, then something needed to go in its place, and that this could become the focus of forward-looking intervention.

7.2.5 Coercive interventions

Coercive interventions were considered in many cases, and sometimes implemented. Many practitioners recognised that the cost of coercive intervention was high, in human terms, and were reluctant to proceed other than in the most extreme circumstances where a basic level of existence is threatened, or risks to others are extreme. In relation to the difficult balance to be struck between respecting autonomy and promoting a duty of care, the default balance for practitioners overall probably tilted towards autonomy, being prepared to envisage extreme personal deterioration if capacity is present and risks to others are not excessive. In contrast, managers were on balance more oriented towards a duty of care and finding the point at which 'something' must be done. In reality, of course, in any individual case, a proportionate balance was sought, often through ongoing debate and intricate reasoning. Where such interventions were unavoidable, practitioners placed strong emphasis on the importance of they themselves being present alongside the service user, to support in whatever way was most appropriate, and of specialist contractors who were experienced in undertaking cleaning or clearing in the context of self-neglect.

7.2.6 Multi-agency working

Within the survey and from the interviews a sense of the value of multi-agency working emerges, but that it has to be continually worked at if it is to reflect fully the

strategic commitments that LSAB partners have entered into. Otherwise, adult social care, the agency to which the majority of self-neglect cases are referred, could be left feeling that it holds all the responsibility. Clear understandings of roles but preparedness to step outside those boundaries where necessary in order to prioritise engagement, plus constant conversation and dialogue between the parties involved, were key markers of good collaboration.

Convening the multi-agency and multi-professional system through risk assessment panels, conference discussions, or just informal case discussion, helped to make self-neglect work 'less mystical, even if still complex' and ultimately more effective. Thus, managers and practitioners talked of the value of case conferences and multi-agency panels, with access to specialists, where different expertise could be applied to scenarios and actions agreed and then followed through and monitored. Here, and in supervision, were opportunities to ensure that practice was compliant with guidance, that information sharing was robust, and that multi-professional agreements were working on the ground.

It was here that, operationally, balances could be struggled with and found between individual choice and autonomy on the one hand, and a duty of care on the other. It was here that the tricky concept of choice could be explored and practitioners enabled to ask challenging questions respectfully about how people might want to live, and what might be the barriers to change. It was here, too, that practitioners could reflect on the tricky issue of consent, namely, when it is acceptable to proceed on the basis of consent previously given until such time as behaviourally it is very clear that the service user has withdrawn it.

7.2.7 Managing the personal experience of self-neglect practice

Effective ways of working in self-neglect have a high cost in terms of impact, particularly for the people who use services and the practitioners who are those most closely involved in interpersonal encounters that can be challenging and distressing, albeit it at times, deeply rewarding. Many of the interviews attest to the raw emotion and depth of feeling that characterises those encounters, and to the deep sense of shared humanity that is generated when a significant empathetic connection is made. Such a connection can be both the means to an end and the end itself. That people who use services often recognise this is evident in their narratives, and similarly practitioners know that this work comes at an emotional cost if they are not well supported. Engaging with sadness and despair, and the poignancy of people's attempts to deal with such feelings, is deeply moving, and feeling helpless yet responsible is a very uncomfortable place to be. Thus, taking responsibility for one's professional support and emotional survival in the work is vital. Equally, managers also have responsibilities to ensure that supervision and support are prioritised, and that they facilitate rather than stifle the creative and brave practice that is often at the heart of the most effective interventions.

7.3 Moving forward

The evidence presented in this report demonstrates how self-neglect is being approached in both policy and practice, documenting managers, practitioners' and service users' experiences of professional interventions and their impact.

The research sought to learn from outcomes in specific cases that were described by those involved as in some way positive, and from these to distil some key indicators

of good practice. In so doing, it has become clear that at the heart of self-neglect practice is a complex interaction between knowing, being and doing:

- Knowing, in the sense of understanding the person, their history, the significance of their self-neglect, along with all the knowledge resources that underpin professional practice.
- Being, in the sense of showing personal and professional qualities of respect, empathy, honesty, reliability, and care, being present, staying alongside, keeping company, being human.
- Doing, in the sense of balancing hands-on and hands-off approaches, seeking the tiny element of latitude for agreement, doing things that will make a small difference while negotiating for the bigger things, and deciding with others when intervention becomes a requirement.

That this is difficult is well established; that it can be done is now evidenced in this report.

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Appendix 1

SURVEY QUESTIONNAIRE

Working with Self-Neglect: A survey of practice and policies

Welcome to the Self-Neglect survey.

Self-neglect poses complex challenges to workers and organisations in the social care field, but relatively little is known beyond individual authorities about how it is currently approached. This survey is intended to gather outline information about the volume, challenges, practice and outcomes of self-neglect cases from local authorities across England, in order to fill this gap. Your input will be valuable in forming a picture of current organisational practice.

The research is funded by the Department of Health. It has ethics approval from the National Social Care Research Ethics Committee (ethics approval reference number 13/IEC08/0013) and the support of the ADASS Research Group (approval reference number Rg13-014).

Taking place at the same time as this survey is a series of interviews with practitioners and service users exploring self-neglect practice in depth. The findings of the survey and interviews, taken together, will contribute to the research evidence base on how beneficial outcomes can be achieved.

If you have any queries about this research project, please contact Professor Suzy Braye, Department of Social Work and Social Care, University of Sussex: s.braye@sussex.ac.uk
If you have any queries about this survey please contact Julie Farlie, Research Coordinator, School of Education and Social Work, University of Sussex: j.farlie@sussex.ac.uk

The survey is open until the 5th December 2013.

If you use this template, you will find details of the return address on the last page. If you prefer to complete the survey online, you will find it at:

<https://www.survey.bris.ac.uk/sussex/selfneglect>

Working with Self-Neglect: A survey of practice and policies

First of all, some information about you. (Responses will be treated in total confidence; no individual survey respondent or authority will be identified in any research reports.)

1. Name:

2. Post:

3. Authority:

A Note on Classification

We recognise that there is no national standard definition of self-neglect. As a result, classifications -- and thresholds in particular -- may differ slightly from area to area. This variation is one of the issues that we are interested in looking at, but for the purposes of this survey our working definition of self-neglect is 'failure, whether deliberate or not, to care for one's self and/or one's environment.' In the research literature, this commonly includes hoarding and living in squalor, as well as neglect of one's own hygiene or well-being.

Volume of Cases

4. Do you routinely collect data on self-neglect?

- ☐ No
☐ Yes
☐ Not specifically but we do collect related data which may be useful

If you answered yes or not specifically, please tell us what kind of data you collect:

5. By either drawing on your data, or (if you do not collect data) giving your best estimate, what is the volume of self-neglect cases being managed by your local authority and/or agencies with which the authority works closely?

6. How confident are you in your answer about the volume of self-neglect cases?

- ☐ Very confident ☐ Fairly confident ☐ Not very confident ☐ Not at all confident

Classification

7. Is self-neglect explicitly defined, or are examples provided, in any of your guidance and/or protocols?

- ☐ No
☐ Yes

If yes, what is/are the definition(s)/ examples, and in what specific guidance / protocol does it occur?

8. Is guidance provided to staff on working with self-neglect?

- ☐ No
☐ Yes

If yes, what guidance is provided and where can it be found?

9. Are there other relevant definitions or examples, not specifically defined as self-neglect but related to it, in any of your guidance and/or protocols? This might include hoarding, living in squalor, or other phenomena that you feel are relevant.

- ☐ No
☐ Yes

If yes, what is/are the definition(s)/ examples, and in what specific guidance / protocol does it occur?

Processes and Outcomes

10. What, in your experience, has been most challenging about self-neglect cases for the authority and/or partner agencies?

11. Is training available to assist staff in working with self-neglect issues?

- ☐ No
☐ Yes
☐ Not specifically

If you answered yes or not specifically, please tell us what kind of training is provided?

12. What processes / pathways are regularly used as ways of working with self-neglect in your locality:
(select all that apply)

- ☐ Safeguarding Alert
- ☐ MARAC
- ☐ Referral to adult social care teams
- ☐ Other (please specify):

13. Is data held on outcomes of self-neglect cases (collectively not individually)?

- ☐ No
- ☐ Yes

If yes, what are the overall outcomes?

14. Has self-neglect been a feature of any Serious Case Reviews undertaken in your area?

- ☐ No
- ☐ Yes

If yes, what were the main messages emerging from these SCRs?

.....

Learning from Practice

In questions 15-18 that follow, we're seeking to learn from examples of good practice

15. Do you know of referral systems and pathways in your area that you feel have worked particularly well either in individual self-neglect cases or with self-neglect more generally?

- ☐ No
- ☐ Yes

If yes, please tell us briefly what you can, about how and why this has been successful.

16. Do you know of mechanisms for interagency collaboration in your area that you feel have worked particularly well either in individual self-neglect cases or with self-neglect more generally?

- ☐ No
☐ Yes

If yes, please tell us briefly what you can about how and why this has been successful.

17. Do you know of procedural guidance or training for staff in your area that you feel have worked particularly well either in individual self-neglect cases or with self-neglect more generally?

- ☐ No
☐ Yes

If yes, please tell us briefly what you can about how and why this has been successful.

18. Do you know of approaches to direct practice in your area that you feel have worked particularly well either in individual self-neglect cases or with self-neglect more generally?

- ☐ No
☐ Yes

If yes, please tell us briefly what you can about how and why this has been successful.

Working with Self-Neglect: A survey of practice and policies

Thank you

This is the end of the survey. Many thanks, your help is much appreciated.

Feedback

20. If you would like to receive feedback on the results of the research, please indicate here:

(Optional)

21. We may be interested in carrying out brief follow-up interviews with a small number of respondents, in order to obtain more in-depth information on some aspects of how you work with self-neglect. Interviews like this would supplement the information gathered through this survey by enabling more detailed discussion of best practice. If you would be willing for us to contact you in the event that this would be useful, please indicate below and provide a telephone and/or e-mail contact. Doing so does not commit you to participating, as you can change your mind later if you wish.

☐ Yes ☐ No

If you answered yes, please let us have your contact details (email and phone).

Email:

Phone:

THANK YOU FOR YOUR PARTICIPATION

PLEASE RETURN THIS COMPLETED DOCUMENT (BY EMAIL ATTACHMENT OR BY POST) TO:

JULIE FARLIE, RESEARCH ADMINISTRATOR, UNIVERSITY OF SUSSEX, SCHOOL OF EDUCATION AND SOCIAL WORK,
ESSEX HOUSE, FALMER, BN1 9QQ

j.farlie@sussex.ac.uk

Appendix 2

TOPIC LISTS FOR INTERVIEWS

TOPIC LIST FOR MANAGER INTERVIEWS

Interviews will be flexibly structured in order to be able to follow up on what is of most interest in each locality. The topics to be covered will include those listed below:

1. What is your management role in the authority?
2. What are your authority's core objectives in relation to self-neglect work?
3. Do you work to a definition of self-neglect? How would you define it?
4. What documentation, protocols, procedures and guidance does your organisation work to in self-neglect work?
5. What data on self-neglect do you collect?
6. What legal powers and duties does the authority work to?
7. Who are your key partners among other agencies in self-neglect work?
8. What mechanisms exist for inter-agency communications?
9. What are the key challenges in achieving objectives in self-neglect work?
10. What helps to overcome those challenges?
11. Does your authority run training for staff specifically on self-neglect work?
12. Has your authority undertaken any management reviews, serious case reviews (SCRs), or other forms of review of self-neglect work? If so, what learning emerged?
13. What are your authority's next priorities in relation to self-neglect work?
14. What would most help you achieve these?

TOPIC LIST FOR PRACTITIONER INTERVIEWS

The purpose of this interview is to elicit practitioners' 'stories' of self-neglect practice they have engaged in that has had (what they would define as) beneficial outcomes. Interviews will be flexibly structured in order to be able to follow the detail of the work that has been done. Practitioners may talk about one case in depth, or several cases, whichever is necessary to illustrate their approach to their work in self-neglect cases.

Introductory information will cover:

- Job role and professional qualification.
- Length of time in post, and in adult social care more generally.
- Training received in self-neglect work.
- Definitions and understandings of self-neglect.

Core questions:

'Please tell me about a piece of work with someone who is or was self-neglectful in which some beneficial outcomes were, or are being, achieved. I'd like to hear about the circumstances in which you got involved, the approaches you took, the challenges you encountered, how you moved towards beneficial outcomes, and what you think has been achieved. If it's helpful, you can talk about several cases.'

Follow-up questions will cover:

- Access to policies, protocols, procedures and guidance.
- Levels of inter-agency collaboration.
- Access to formal mechanisms to support casework and decision making.
- The impact of the work and access to supervision and support.
- Lessons to be drawn from their experience with self-neglect work, and any advice they would give others doing similar work.

TOPIC LIST FOR INTERVIEWS WITH PEOPLE WHO USE SERVICES

The purpose of this interview is to give people who use services the opportunity to share their experience of:

- living in circumstances that have involved lack of self-care or care of their living environment; and
- using adult social care services to help manage those circumstances.

The interviews will be unstructured, allowing the interviewee to provide direction, and responding to the user's preferred mode and pace of discussion. Topics to be covered are:

- What it is, or was, like living in the circumstances that amounted to self-neglect.
- Who supports/supported them at home.
- How and why they became involved with the practitioner who has been working with them.
- How they felt about that involvement, at the beginning.
- What kind of support has been provided.
- Whether any aspects of it have been beneficial, and in what way.
- Whether any aspects of it have been less helpful.
- Is there anything they think should have been done differently?
- What they feel about their circumstances now.
- If things are different, what's made the difference?
- How they see their circumstances developing in the future.

Appendix 3

Information sheets for participants



INITIAL LETTER

Dear Director

Invitation to join Department of Health-commissioned research into self-neglect practice

We're writing to invite your authority to take part in a research study on the topic of self-neglect. The Department of Health has commissioned the University of Sussex and the University of Bedfordshire to explore how local authorities' policies and practices can support beneficial outcomes in cases of self-neglect. The study builds on the previous research we conducted for the Department of Health, published in 2011.²

The new research seeks to identify, first, what approaches local authorities across England use in responding to self-neglect; that strand of the research is being carried out through a national survey. The second strand of the research is an in-depth exploration of self-neglect practice in six local authorities, in both urban and rural environments, seeking through interviews and documentary evidence to:

- a) identify accounts from practitioners and, where possible, people who use services, that demonstrate how self-neglect practice can support individually beneficial outcomes;
- b) identify procedural frameworks that enable practitioners and their managers to respond to the challenges posed by self-neglect;
- c) identify common features that allow key indicators of constructive policy and practice to emerge.

We would like to invite your authority to participate in the second strand of the research: the in-depth exploration. We have by invitation worked with your staff to share the outcomes of the previous research, and we're aware of the work being done to develop good practice. The research would involve a series of individual interviews – two with managers (perhaps one at strategic level and one at operational level), between 4–6 with practitioners, and potentially the same number with people who use services – in order to hear about approaches to self-neglect work. No authority taking part in the study, or any individuals, will be named or identified in the report. All members of the research team involved in undertaking interviews will have undergone satisfactory checks through the Criminal Records Bureau. The study has approval from the

² Braye, S., Orr, D. and Preston-Shoot, M. (2011) *Self-neglect and adult safeguarding: Findings from research*, London: Social Care Institute for Excellence.

national Social Care Research Ethics Committee (ethics approval reference number 13/IEC08/0013).

We hope you will be interested for your staff to work with us on this study. There may, of course, be questions you wish to have answered before deciding; we're suggesting that if you would like to consider taking part, we have a telephone discussion with yourself, or a lead manager you nominate. This would enable us to answer any queries or concerns you may have, and also, importantly, take your advice on how we might best approach the visit to your particular locality.

We look forward to hearing from you.

Best regards

A handwritten signature in black ink, appearing to read 'Suzy Braye', with a stylized flourish at the end.

Professor Suzy Braye and Dr David Orr, University of Sussex
s.braye@sussex.ac.uk, d.orr@sussex.ac.uk

Professor Michael Preston-Shoot, University of Bedfordshire
michael.preston-shoot@beds.ac.uk

SELF-NEGLECT RESEARCH MANAGERS' INFORMATION SHEET

Key contact: Professor Suzy Braye, University of Sussex, Falmer, Brighton, BN1 9QQ

Tel: 01273 876648; email: s.braye@sussex.ac.uk

Study title

Self-neglect practice

Invitation

We are inviting you to take part in our research study. This information sheet explains why the research is being done and what it involves. If you decide to take part, a member of the research team will go through the information sheet with you and answer any questions you have. Please ask us if anything isn't clear.

What is the purpose of the study?

The term 'self-neglect' covers a range of behaviour that in different ways shows unwillingness or inability to care for oneself, and/or for one's home. These can include hoarding, lack of personal care and levels of cleanliness or infestation that pose severe risks to health and wellbeing. When this happens, it is sometimes hard for adult social care services to find a way to help, and to support the individual in managing the risks involved. We have been asked by the Department of Health, the government body responsible for adult social care, to explore what policies and practices in situations involving self-neglect can help achieve beneficial outcomes for those involved.

We are visiting six different localities to learn from managers, practitioners and people who use services about their experience of providing and using services, in the hope that we can identify those approaches. Your authority has agreed to take part.

Why have I been invited to participate?

You have received this invitation to participate in the research because it has been suggested you have management experience that includes responsibility for self-neglect work. We are hoping to interview two managers in your authority, as well as between four and six practitioners and a similar number of people who use services.

What will happen if I take part?

You will be invited to meet with a member of the research team for an individual discussion. (The research team member will have undergone satisfactory checks through the Criminal Records Bureau.) The researcher will ask you about your experience of managing a service that involves work with self-neglect, and will ask you to tell us about approaches that have been beneficial. The discussion will take around an hour, and if you agree we will make a recording to make sure we can accurately note your views. Of course, if you decide to take part, you are still free to withdraw at any time and without giving a reason.

What are the possible disadvantages and risks of taking part?

We do not believe there are any risks to you of taking part in the research, although a disadvantage is that taking part in the discussion with us will use your time.

What are the possible benefits of taking part?

We believe the potential benefits to adult social care practice are significant. The research report to the Department of Health will, we hope, provide markers of positive practice. For these markers to be informed by those with direct knowledge and experience of self-neglect will enhance their value and impact. Your participation will help to further current levels of understanding about intervention in self-neglect. At an individual level, it can be beneficial to have the time and space for a reflective discussion about practice, and people do sometimes say that a research interview provides them with this opportunity.

Will my information in this study be kept confidential?

All information you provide about yourself or about anyone else will be kept confidential; any recording of the discussion, or notes, will be safely stored in a secure environment and destroyed once the research is complete. Views expressed in the discussions will be used anonymously in our research report and in any other publications or presentations, and will not be attributed to any one individual. No participating authority will be named. The one exception to confidentiality is information that indicates a vulnerable third party is at risk and appropriate measures are not being taken; here we will refer to the appropriate authority for assessment of the need for protective action, but only after talking with you about it first.

What will happen to the results of the research study?

The research will be used to inform our report for the Department of Health. Findings will be published in academic journals and presented at conferences.

Who is organising and funding the research?

The researchers are members of staff in the School of Education and Social Work at the University of Sussex and the Faculty of Health and Social Sciences at the University of Bedfordshire. The research is being funded by the Department of Health.

Who has approved this study?

The research has been approved by the national Social Care Research Ethics Committee, approval reference number 13/IEC08/0013.

Contacts for Further Information

Please let us know if you would like to take part in an interview, or would like to discuss further before you decide; we look forward to hearing from you.

- Professor Suzy Braye, University of Sussex, School of Education and Social Work
Tel: 01273 876638; email: s.braye@sussex.ac.uk
- Dr David Orr, University of Sussex, School of Education and Social Work
Tel: 01273 678167; email: d.orr@sussex.ac.uk
- Professor Michael Preston-Shoot, University of Bedfordshire, Faculty of Health and Social Sciences
Tel: 01582 743251; email: Michael.preston-shoot@beds.ac.uk

Who to contact if you want to complain about the research

- Professor Brian Hudson, Head of School of Education and Social Work, University of Sussex, Falmer, Brighton, BN1 9QQ
Tel: 01273 872729; email: b.g.hudson@sussex.ac.uk

Thank you

Thank you for taking the time to read this information sheet.

SELF-NEGLECT RESEARCH PRACTITIONERS' INFORMATION SHEET

Key contact: Professor Suzy Braye, University of Sussex, Falmer, Brighton, BN1 9QQ

Tel: 01273 876648; email: s.braye@sussex.ac.uk

Study title

Self-neglect practice

Invitation

We are inviting you to take part in our research study. This information sheet explains why the research is being done and what it involves. If you decide to take part, a member of the research team will go through the information sheet with you and answer any questions you have. Please ask us if anything isn't clear.

What is the purpose of the study?

The term 'self-neglect' covers a range of behaviour that in different ways shows unwillingness or inability to care for oneself, and/or for one's home. These can include hoarding, lack of personal care and levels of cleanliness or infestation that pose severe risks to health and wellbeing. When this happens, it is sometimes hard for adult social care services to find a way to help, and to support the individual in managing the risks involved. We have been asked by the Department of Health, the government body responsible for adult social care, to explore what policies and practices in situations involving self-neglect can help achieve beneficial outcomes for those involved. We are visiting six different localities to learn from managers, practitioners and people who use services about their experience of providing and using services, in the hope that we can identify those approaches. Your authority has agreed to take part.

Why have I been invited to participate?

You have received this invitation to participate in the research because you have experience of working in a role in which you meet self-neglect. We are hoping to interview between four and six practitioners in your authority and a similar number of service users, as well as up to two managers.

What will happen if I take part?

You will be invited to meet with a member of the research team for an individual discussion. (The research team member will have undergone satisfactory checks through the Criminal Records Bureau.) The researcher will ask you about your experience of providing a service to a person who is self-neglectful in ways that have been beneficial. The discussion will take around an hour, and if you agree we will make a recording to ensure we can accurately note your views.

We are hoping that the service user also will be willing to meet with the researcher (provided they have mental capacity to consent to this) to talk about their experience of self-neglect, and what professional approaches have made a difference for them. We will ask you to consider helping us to make contact with them. There has been very little research on the views of people who self-neglect, yet we believe their views can contribute to better understanding. Of course, we will still want to hear your own views, even if the service user does not participate,

and if you decide to take part, you are still free to withdraw at any time and without giving a reason.

What are the possible disadvantages and risks of taking part?

We do not believe there are any risks to you of taking part in the research, although a disadvantage is that taking part in the discussion with us will use your time.

What are the possible benefits of taking part?

We believe the potential benefits to practice are significant. The research report to the Department of Health will, we hope, provide markers of positive practice. For these to be informed by the views of practitioners and people who use services with direct knowledge and experience of self-neglect will enhance their value and impact. Little research has been done in England on self-neglect practice, and the involvement of service users is very rare indeed. Your participation will help to take further current levels of understanding about intervention in self-neglect. At an individual level, it can be beneficial to have the time and space for a reflective discussion about practice, and people do sometimes say that a research interview provides them with this opportunity.

Will my information in this study be kept confidential?

All information you provide about yourself or about anyone else will be kept confidential; any recording of the discussion, or notes, will be safely stored in a secure environment and destroyed once the research is complete. Views expressed in the discussions will be used anonymously in our research report and in any other publications or presentations, and will not be attributed to any one individual. No participating authority will be named. The one exception to confidentiality is information that indicates a vulnerable third party is at risk and appropriate measures are not being taken; here we will refer to the appropriate authority for assessment of the need for protective action, but only after talking with you about it first.

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Who is organising and funding the research?

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Who has approved this study?

The research has been approved by the national Social Care Research Ethics Committee, ethics approval reference number 13/IEC08/0013.

Contacts for Further Information

Please let us know if you would like to take part in an interview, or would like to discuss further before you decide; we look forward to hearing from you.

- Professor Suzy Braye, University of Sussex, School of Education and Social Work
Tel: 01273 876638; email: s.braye@sussex.ac.uk
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Tel: 01273 872729; email: b.g.hudson@sussex.ac.uk

Thank you

Thank you for taking the time to read this information sheet.

**SELF-NEGLECT RESEARCH
INFORMATION SHEET FOR PEOPLE WHO USE SERVICES**

Key contact: Professor Suzy Braye, University of Sussex, Falmer, Brighton, BN1 9QQ

Tel: 01273 876648; email: s.braye@sussex.ac.uk

Study title

Self-neglect practice

Invitation

We are inviting you to take part in our research study. This information sheet explains why the research is being done and what it involves. If you decide to take part, the researcher will go through the information sheet with you and answer any questions you have. Please ask us if anything isn't clear.

What is the purpose of the study?

When professionals worry that a person is not caring for themselves or for their home, they sometimes call it 'self-neglect'. This might mean that they are concerned that the person is not looking after their own health or personal care. Or they may be concerned that the person is not tidying, cleaning or throwing things away for so long that their home becomes risky for their health or wellbeing.

When this happens, it is sometimes hard for adult social care services to find a way to help, and to support that person to manage the risks involved. We have been asked by the Department of Health, the government body responsible for adult social care, to explore how best to help people in situations of self-neglect. The research will help everyone understand what makes a positive difference for those involved.

We are visiting adult social care teams to learn from professional staff and from people who use services about their experience of providing and using services. We hope to find out about what works well in self-neglect. The local authority where you live has agreed to take part.

Why have I been invited to participate?

You have received this invitation to take part in the research because the professional supporting you believes we can learn a lot from your personal experience. We would like to understand what you think about the services you have received to help you manage.

What will happen if I agree to take part?

We will invite you to meet a member of the research team for an individual discussion. We would like to understand what you think about the services you have received. (The researcher will have been checked by the Criminal Records Bureau to make sure they are suitable to do this work.) The researcher will meet you at the most suitable place, either at home or at a place you choose. The discussion will take up to an hour, and we can take breaks, too, if you prefer. We will, if you agree, make a recording to make sure we accurately note your views. We will give you £25 as a thank you for the meeting, and we will meet travel expenses or other costs.

If you decide to take part, you are still free to withdraw at any time and without giving a reason. If during the discussion we believe you can no longer understand and give your consent, we will not ask you any more questions, and we will only keep the information you have given us up to then.

What are the possible disadvantages and risks of taking part?

We do not believe there are any risks to you of taking part in the research, but it is possible that talking about your experience will make you feel upset for a time. If this happens, we can stop at any time, and we will make sure you have someone who can help you with those feelings afterwards.

What are the possible benefits of taking part?

Very little research has been done in England on self-neglect, and the involvement of people who have used services is very rare indeed. We think your contribution will make a difference to how professionals understand self-neglect, and what helps to support people.

Will my information in this study be kept confidential?

We will keep confidential all information you provide about yourself or anyone else. We will only tell someone else what we have discussed if we think you or another person is at risk. If that happens, we will tell someone who can help, but only after we have talked with you about it first. Any recording or notes of our discussion will be securely stored and destroyed once the research is complete. We will make sure that your name and where you live cannot be identified in any report.

What will happen to the results of the research study?

We will write a report for the Department of Health. The report will help health and social care services improve how they support people who are self-neglectful. We will write short reports for publication in academic journals and make presentations at conferences.

Who is organising and funding the research?

The researchers are members of staff in the School of Education and Social Work at the University of Sussex and the Faculty of Health and Social Sciences at the University of Bedfordshire. The research is being funded by the Department of Health.

Who has approved this study?

The research has been approved by the national Social Care Research Ethics Committee, ethics approval reference number 13/IEC08/0013.

Contact the researchers for further information

Please let us know if you would like to take part in an interview, or would like to discuss further before you decide; we look forward to hearing from you.

- Professor Suzy Braye, University of Sussex, School of Education and Social Work
Tel: 01273 876638; email: s.braye@sussex.ac.uk
- Dr David Orr, University of Sussex, School of Education and Social Work
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- Professor Brian Hudson, Head of School of Education and Social Work, University of Sussex, Falmer, Brighton, BN1 9QQ
Tel: 01273 872729; email: b.g.hudson@sussex.ac.uk

Thank you

Thank you for taking the time to read this information sheet.

Self-neglect policy and practice: building an evidence base for adult social care

This research, commissioned by the Department of Health (DH), set out to identify what could be learned about current policy and practice in self-neglect, experienced as a highly challenging aspect of contemporary adult social care. A national (England) survey investigated current strategic and policy initiatives, with responses from 53 out of 152 local authorities (34.9 per cent). A series of in-depth interviews undertaken with 20 managers, 42 practitioners and 29 people who use services across 10 authorities identified approaches that have produced positive outcomes from the perspectives of those involved.

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