

Self-neglect policy and practice: research messages for managers



The research on which this briefing is based set out to identify what could be learnt from policies and practices that have produced positive outcomes in self-neglect work, from the perspectives of key groups of stakeholders – practitioners and managers in adult social care and in safeguarding, and people who use services.

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Summary

The research on which this briefing is based set out to identify what could be learnt from policies and practices that have produced positive outcomes in self-neglect work, from the perspectives of key groups of stakeholders – practitioners and managers in adult social care and in safeguarding, and people who use services.

Self-neglect practice was found to be more successful where practitioners:

- took time to build rapport and a relationship of trust, through persistence, patience and continuity of involvement
- tried to 'find' the whole person and to understand the meaning of their self-neglect in the context of their life history, rather than just the particular need that might fit into an organisation's specific role
- worked at the individual's pace, but were able to spot moments of motivation that could facilitate change, even if the steps towards it were small
- ensured that they understood the nature of the individual's mental capacity in respect of self-care decisions
- were honest, open and transparent about risks and options
- had in-depth understanding of legal mandates providing options for intervention
- made use of creative and flexible interventions, including family members and community resources where appropriate
- engaged in effective multi-agency working to ensure inter-disciplinary and specialist perspectives, and coordination of work towards shared goals.

In turn, the organisational arrangements that best supported such work included:

- a clear location for strategic responsibility for self-neglect, often the Local Safeguarding Adults Board (LSAB)
- shared understandings between agencies of how self-neglect might be defined and understood
- data collection on self-neglect referrals, interventions and outcomes
- clear referral routes
- systems in place to ensure coordination and shared risk management between agencies
- time allocations that allow for longer-term supportive, relationship-based involvement
- training and practice development around the ethical challenges, legal options and skills involved in working with adults who self-neglect
- supervision systems that both challenge and support practitioners.

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 and 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, care, being present, staying alongside and keeping company
- **doing**, in the sense of balancing hands-off and hands-on 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.

Introduction

Self-neglect has emerged as a significant challenge to practitioners and policy makers across a range of agencies. 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. Self-neglect encompasses a complex and individualised interplay between mental, physical, social and environmental factors. However, while certain recommendations about practice in the field of self-neglect recur regularly in the literature and serious case reviews – 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 has been lacking, particularly within the English context.

Self-neglect has occupied an ambivalent position in relation to adult safeguarding. Until now, many LSABs have explicitly excluded self-neglect from the remit of their safeguarding procedures – a position consistent with historical *No secrets* guidance (Department of Health, 2000), which focused on harm caused by a third party – although in some locations parallel systems for the management of risk have existed, sometimes under the overall remit of the LSAB. However, statutory guidance on the Care Act 2014 (Department of Health, 2014) introduces significant change by including self-neglect in the list of circumstances that constitute abuse and neglect, thus strengthening links with the work of LSABs, which are themselves now constituted on a statutory basis.

Practitioners and managers have reported a number of challenges in this field of work (Braye et al, 2011, 2013), including how to define self-neglect and where best to locate it strategically and operationally. The work is perceived as complex and high risk, complicated by:

- divergent agency thresholds for triggering concern and involvement
- competing value perspectives
- unclear legal frameworks
- care management workflow arrangements.

What practitioners and managers have emphasised is their need for knowledge about, and skills for effective interventions with, adults who self-neglect, located within organisational structures that offer:

- space and time for building relationships with people who use services
- opportunities for reflective supervision
- arrangements to facilitate creative practice and shared risk management and decision making.

Practitioners and managers have sought 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. Yet, evidence of successful outcomes from policy and practice approaches that have been employed has been lacking.

The present research briefing for managers seeks partly to fill this gap, drawing on research commissioned by the Department of Health, which included a national survey of local authorities and in-depth interviews with people who use services, practitioners and managers in adult social care. For full details of the project, its findings and conclusions, see Braye et al (2014). This briefing highlights the salient findings for managers. It begins with defining self-neglect and then looks at specific aspects of strategy and governance, including the location of self-neglect within adult safeguarding, the commissioning of reviews, and the development of policies for self-neglect. Following this, the briefing becomes more operational, focusing on building multi-agency cooperation, configuring effective referral pathways and supporting frontline practice. Two further briefings – one for practitioners and one for a broader audience, including people who use services, carers and non-specialist staff – are also available (see Braye et al, 2015a, 2015b).

Defining self-neglect

The challenge of defining self-neglect has proved a barrier in the development of policies and procedures and so moving towards a national definition of self-neglect might be helpful. Previous research on self-neglect (Braye et al, 2011) was used as the basis for exploring the parameters of policy and practice in the present study and, for definitional purposes, self-neglect in the study includes adults both 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, and/or
- refusal of services that would mitigate risk of harm.

However, as people who use services and practitioners observed in this research project, there is no typical self-neglect case. Stark contrasts emerge between those neglecting themselves and those neglecting their home environments, and between different types of, and reasons for, hoarding. Self-neglect may be a longstanding pattern or a recent change and be linked to loss, past trauma and/or low self-esteem. People may be at risk from other people and their responses shaped by rationalisation, shame or denial. Professional interest in an individual's self-neglect, triggered by the level of harm or risk associated with the behaviour, may be at odds with the individual's own perception of the behaviour. Flexibility of response, informed by an understanding of each unique case, is one key ingredient of effective practice.

Data collection

Few local authorities collect data on the volume and outcomes of self-neglect work, although many teams work with such cases on a daily basis. Local authorities responding to the survey gave estimates but no formal quantification of the volume of cases. These estimates varied widely, aggravated by problems of definition. Gathering such data might be complex when cases are managed by a variety of teams and agencies. However, data collection enables agencies and the LSAB to have an overview of self-neglect work and to quantify the size of the challenge posed by self-neglect. Tracking cases' outcomes adds to the evidence base of effective practice by making possible an evaluation of the outcomes of capacity assessments, risk management plans and individualised multi-agency interventions. Data collection also enables consideration to be given to whether the available workforce has the necessary knowledge and skills.

Triggers for LSAB and management action

A focus on policy and practice development for working with adults who self-neglect has been prompted in various ways. Some LSABs have commissioned and/or completed serious case reviews (SCRs) that have recognised this field of work as challenging and recommended procedural development and service improvement, for example regarding capacity assessments and information-sharing. Concerns and criticisms have sometimes been expressed by coroners, courts, ombudsmen and partner agencies and triggered inter-agency discussions and pilot arrangements. Complex cases involving substantial risks and polarised professional value positions about self-determination and duty of care, coupled with staff anxiety, have indicated the need for a policy and management of practice framework that provides a sense of containment or security for staff who may additionally have expressed concern about their levels of knowledge, skill and confidence for working with self-neglect cases.

Locating strategic oversight of self-neglect

To focus attention on self-neglect as a strategic issue, some LSABs have assumed responsibility for governance and policy development. This has the advantage of drawing on existing multi-agency structures and partnership activity. Sub-groups have sometimes been assigned specific responsibility, for instance to develop a training plan or protocols on mental capacity assessments. This approach gives institutional force to self-neglect being a multi-agency responsibility and prompts ownership of the issue among partner agencies. Locating the development and signing off of self-neglect protocols, procedures and practice guidance within LSABs is a means of providing a framework for practice in an area of work that practitioners find stressful, challenging and complex, ensuring agency buy-in and promoting accountability.

Commissioning reviews

Just over one quarter of local authorities responding to the survey knew of an SCR on self-neglect in their area, while others referred to single or multi-agency case reviews as a means of organisational learning. Key messages from SCRs were:

- the importance of thorough and timely capacity assessments, communication and information-sharing
- awareness of the impact of chronology and historical factors on a person's current presentation
- the need for joint working to manage risk
- the need for assertive care plans that seek to engage with individuals who are reluctant to accept help.

SCRs had also stressed the importance of escalation of concerns about single or multi-agency practice in particular cases, to ensure that senior managers are aware of high-risk cases, and had emphasised the importance of genuine multi-disciplinary engagement as opposed to reliance solely on adult social care input. Some respondents 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 identification of self-neglect, working with service refusal and disengagement, understanding mental capacity and risk assessments. Practitioners appreciated the learning for practice that can be extracted from SCRs but this potential is restricted currently by the difficulty of locating them (Braye et al, 2015c).

Policy development

Some local authorities (over half responding to the survey), with their statutory partners, have developed policies and procedures for working with adults who self-neglect, underpinned by definitions of self-neglect, sometimes adding specific protocols on topics such as hoarding, service refusal and high-risk cases. Evident too in a number of authorities are high-risk management models, in some cases specific to self-neglect while in others self-neglect is included among other high-risk circumstances covered. Such models encourage joint working to gather information and capability from all agencies, and usually set in place:

- a multi-agency protocol that offers clear principles and values
- a framework (often including a panel) for shared assessment and management of risk
- guidance on core elements of practice that will underpin high-risk work in all agencies in the LSAB area, in some cases including flow charts to guide decision-making.

The guidance typically requires the following:

- 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.

Sometimes these policies, together with others on topics such as information-sharing, have 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, police and acute hospitals, which serve a wide geographical area. Here, different approaches across local authority areas with respect to governance can create complications and delay, but this joint approach is also felt to facilitate agency engagement in adult safeguarding. Indeed, practitioners perceive guidance as helping to engage agencies, to provide consistency of practice, and to maintain involvement in complex cases.

However, agreeing policies across agencies does not necessarily guarantee across-the-board implementation, illustrating the need for LSABs to work continuously at ensuring multi-agency partnership working. Procedures and guidance provide frameworks for practice and raise awareness, but their implementation can be derailed by the following:

- policy overload
- lack of joint working
- workload demands
- staff turnover
- limited knowledge and understanding of policy intentions.

Simply having a procedure does not ensure sound practice, because knowing that a policy exists is different from developing an understanding of its content (Northway et al, 2007). Consequently, a focus on workforce and workplace development, where the former emphasises the provision of training and supervision and the latter how organisational and inter-agency cultures and systems affect practice, is necessary (Braye et al, 2013).

Thus, LSABs need to resolve the ambiguity of the position that self-neglect occupies strategically in relation to adult safeguarding. Once the location for strategic development and oversight or review is determined, to be meaningful the status of resulting protocols and procedures also needs to be clarified.

Building multi-agency cooperation

Inter-agency communication and cooperation, while improving, remains variable strategically and operationally. Six areas emerged from this research as particularly important.

Getting sign-up

To build and maintain multi-agency relationships requires time, trust, focus and a willingness to challenge practices.

Locating self-neglect within overarching multi-agency structures

Locating self-neglect within overarching multi-agency structures facilitates strategic engagement and buy-in, and operational familiarity with inter-agency working. A lead and subsequent oversight from the LSAB appears 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 ties agencies into processes for practitioners and operational managers to follow.

Systems used to facilitate multi-agency working

An explicit high-risk management approach, agreed at board level, helps to secure multi-agency cooperation operationally. Once again, LSAB endorsement lends authority and credibility to this way of working with adults who self-neglect. Working strategically to agree such an operational system brings benefits in terms of:

- efficient use of resources
- a challenge to threshold-bouncing (where different thresholds influence whether an agency can respond) and silo working (where a person's needs are not considered holistically)
- more coordinated and effective interventions.

Debating different perspectives on ethical dilemmas

Building multi-agency systems can be a challenge because of the ethical dilemmas involved when working with adults who self-neglect. Managers and practitioners 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 emerge as potential obstacles to securing both strategic and operational collaboration. Debating ethical challenges in the LSAB supports the search for agreement on a joint approach.

Assigning lead manager/agency responsibility

Assigning lead manager/agency responsibility is recommended in SCRs for complex cases (Braye et al, 2015c). A wide variety of agencies must participate alongside adult social care in building collaboration in respect of self-neglect because of the variety of

triggers and risks involved, including health commissioners and providers, mental health, learning difficulties services, environmental health, police, the fire service and housing. The concept of key roles is useful, distinguishing between those agencies and professionals who are at the frontline of recognising cases of self-neglect and those who could take the lead in any subsequent assessment and intervention.

Monitoring how particular agencies are participating

Investment in building multi-agency collaboration at a strategic level generates operational benefits in terms of agencies working together to safeguard and promote people's wellbeing, reflected in referrals and escalation of concerns. Persuading some agencies that self-neglect is not just a local authority responsibility can be challenging. Here, self-neglect champions and pre-established relationships can facilitate multi-agency working at strategic and operational levels.

Configuring referral pathways

Strategic development of service approaches includes a focus on referral pathways, how cases of self-neglect find their way into local authority settings, and subsequently on the management of the work referred. This is one aspect of agreeing a multi-agency approach to self-neglect work and affords a structured approach that people can see and follow.

Without an agreed approach, the existence of a variety of referral routes leads to inconsistent responses that can deter subsequent referrers. Equally, referrers will not necessarily know where to refer concerns or how to follow them up. Threshold-bouncing and silo working are also more likely.

Agreed pathways will depend on how a local authority and its partner agencies organise their teams, especially if safeguarding staff are co-located. Integrated health and social care teams may facilitate ownership of self-neglect cases and co-working. Pathways will also be influenced by:

- client presentation
- case complexity
- the risks identified
- the individual's views about preferred agencies and workers
- whether self-neglect is accompanied by neglect by another person.

Specific pathways may be agreed for cases involving, for example, fire risk or dementia, or pathways may lead into adult safeguarding for high-risk cases where multi-agency approaches have failed to make progress in managing risks and addressing care needs. Threshold criteria might have to be treated flexibly rather than rigidly enforced to avoid adult social care becoming the default referral location and to enable the agency with the best access to the individual to continue to engage. In sum, the best pathway is flexible and responsive to individual need, with access to adult safeguarding specialists defined for those cases where other agencies or teams are working with adults who self-neglect.

Ongoing work needs to be supported. Multi-agency involvement in subsequent work is facilitated by case discussions, high-risk panels or network meetings where progress can be reviewed and additional referrals made where necessary. These:

- facilitate inter-agency communication
- enable prompt assessment of capacity and risk
- allow follow-through on action plans to be scrutinised
- enable access to specialist expertise.

Turning strategic commitments into frontline practice

Arriving at strategic commitments about referral pathways 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 are, similarly, only half the story at best; the lessons for good practice have to be effectively disseminated and their outcomes tracked. Strategic mechanisms for this are structured here under four themes:

- training
- guidance
- approaches to learning and service development
- access to specialists.

Training

One challenge is to ensure that training is offered; only one fifth of local authorities responding to the survey identified the availability of training on self-neglect issues. A further challenge is to ensure that learning transfers into effective practice. The research evidence suggests that more attention could be paid in practice development programmes to the ethical challenges, legal options and skills involved in working with adults who self-neglect. Topics that should be covered include:

- the Mental Capacity Act 2005 and other possible legislative responses to self-neglect
- skills in capacity and risk assessments
- skills in best interests decisions
- skills in investigative interviewing and respectful challenge.

Research findings on hoarding, the conclusions of SCRs and the perspectives of people who use services are informative in building a knowledge base of good practice. Particularly effective training is interactive and involves practitioners from a range of agencies; it is built around case studies that facilitate exploration and reflection. Learning should not just depend on external experts presenting at conferences; it can be greatly facilitated by staff giving case presentations to peers and colleagues and receiving feedback. Learning will be embedded more effectively in practice if tracked through supervision and if time is officially allocated for reflection and research. Further guidance on workforce and workplace development is available (see Braye et al, 2013).

Guidance

The rationale for developing guidance on self-neglect and on its specific manifestations, such as hoarding, is that significant risks can be present in these cases. Such cases require judgement calls from practitioners, including knowing when to escalate when the risks are high. Guidance needs to acknowledge how slippery the concept of self-neglect

can 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 is recognition of how powerless workers can feel when faced with individuals at serious risk but where the legal framework acknowledges their capacity to make unwise decisions. Guidance designed to place their practice within a structured framework, for example when working with people with fluctuating capacity who are in need but will not engage, helps practitioners to feel safe in their practice. It should cover:

- definitions
- available legal options
- risk and capacity assessments
- responses to service refusal
- ethical dilemmas
- what to consider when balancing respect for autonomy with a duty of care.

Supervision, case discussions, network meetings and training will then all be necessary to ensure that guidance is understood and followed. LSAB endorsement facilitates adoption across agencies.

Approaches to learning and service improvement

Various approaches help to bring self-neglect to the forefront, to inform protocol and practice development, and to embed a multi-agency response. These include:

- reflective groups
- conferences
- specialist panels for high-risk cases
- audits of referrals and casework.

These approaches inject energy into policy and practice development, and address the anxiety, stress and isolation that practitioners often experience when working with adults who self-neglect. For example, they provide support when thinking through ethical and legal complexities that can be involved, and facilitate the dissemination of learning from SCR findings.

Access to specialists

Access to lawyers can prove very useful as a way of ensuring that the legal bases are covered when offering services. Not all local authorities, however, allow such unrestricted access to legal advice; an internal market has attendant cost implications. Access to specialists in safeguarding, mental capacity, deprivation of liberty safeguards and mental health assessment also supports staff to manage the complexities of working with adults who self-neglect. Specialists can support by:

- providing advice
- offering training

- undertaking joint visits
- attending case conferences
- facilitating case discussions
- contributing to protocol development.

Experiences of putting strategy into practice

The particular operational challenges raised by managers in the research, and their perspectives on ways in which they are being addressed, are organised here into themes:

- care management
- multi-professional working
- panel meetings and case conferences
- compliance with guidance
- effective engagement with adults who self-neglect
- staffing and support
- capacity
- legal literacy
- effective interventions.

Care management

Practitioners should be able to work with people who use services in a personalised and, where necessary, protective way, regardless of organisational approach to workflow, and a 'one size fits all' approach to adult social care is seen as inappropriate. Respondents recognised that self-neglect cases do not fit neatly into care management, reablement or personalised budget approaches to workflow, requiring staff with skills, persistence and experience to work in a long-term way with people reluctant to engage. Flexibility is crucial for self-neglect cases within organisational approaches to work distribution, including timeframes for assessment and decision making about thresholds and packages of care, and procedures for closure or transfer of cases between teams. Operationally, the need for flexibility also extends to the allocation of self-neglect cases to adult social care, specialist or adult safeguarding teams. This depends on the complexity of the case and the nature of the self-neglect being presented. One particular complexity arises in situations where self-neglect is accompanied by neglect from a partner or carer. This requires skilled work to understand the dynamics between the adults involved and to avoid distortion of focus and attention.

Multi-professional working

Communication between professionals is crucial, drawing on a wide pool of expertise to develop an understanding of a situation. But communication within and across agencies can be complicated by different understandings of what leads people to self-neglect and pre-judgements about misuse of alcohol and drugs, about the motivation of repeat callers to emergency services and about acceptable home standards. This can affect the willingness of agencies to retain involvement when, as is often the case, long-term work is required. Communication challenges also arise between agencies where one agency states that a case does not meet their threshold criteria and where there is a

perceived expectation that adult social care will “*fix the problem*”. Relationships at the frontline are variable and require the investment of time and commitment.

Several factors, though, do appear to facilitate joint working, namely:

- co-location
- adult social care staff being prepared to time meetings to facilitate the involvement of other agencies
- adult social care staff being prepared to chase up reports
- a history of good multi-agency cooperation that has been supported by particular personalities.

An integrated health and social care system, where it exists, can remove barriers to organisational interaction and facilitate joint working, for example through attending each other's team meetings and joint triage of referrals to enable agreed decisions on responses to referrals. Risk panels and network meetings provide opportunities to:

- share information
- work through any tensions surrounding whether and how to intervene
- identify the practitioner most likely to be able to engage the individual and to facilitate the involvement of other agencies and professionals thereafter.

Panel meetings and case conferences

Social workers and other professionals find it helpful to bring self-neglect cases they experience as challenging to multi-professional panel meetings or case conferences and so they are an important investment in terms of time and personnel and raise the profile of self-neglect. Panel meetings and case conferences are key mechanisms for working together, helpful because:

- they get people talking about the issues in cases and possible interventions to resolve them
- professionals are in contact with each other to focus on reaching a workable plan with clear duties and responsibilities
- the meetings/conferences coordinate decision making and the work effort rather than allowing a situation to persist where individual agencies are working in isolation and pursuing their own interventions, sometimes in ignorance of what others are doing
- the level of anxiety that self-neglect cases generate can be high, especially when someone appears to have capacity and is making unwise decisions, or where capacity is uncertain, and professionals value the input of the meetings/conferences.

Good practice revolves around:

- the sharing of risk assessments and action plans that seek to minimise the assessed risks
- consideration of the legal options available to different agencies and the circumstances in which these mandates might be used
- the circulation of agreed notes and decisions, with progress chasing by whichever agency or professional is given lead responsibility.

Compliance with guidance

Procedures can be helpful operationally, for example in securing attendance by agencies at panel meetings or conferences. However, concerns about participation may have to be escalated to senior managers and/or the LSAB if particular professionals do not cooperate. Practitioners report that guidance has facilitated inter-professional working.

Effective engagement with adults who self-neglect

Work is more likely to be effective when thought is given to how one engages and how one demonstrates professional values such as respect and dignity. The work begins with, and has to prioritise, trust and relationship-building with people who are resistant to accepting any type of care. This can mean *'revisiting and revisiting, and talking with them ... with cases like that you need to make the time. Otherwise there's no point'*. It may mean showing *'real persistence'* and tenacity in seeking to develop rapport and a relationship, get across the threshold and begin to effect some improvements in someone's living situation. At times it can involve gentle insistence or even straight talking at times of crisis. It can mean sharing one's recording of the situation with the person in order to facilitate discussion of needs, concerns and risks. These approaches are linked to a duty of care, trying to improve outcomes for people by continuing to engage.

Examples were given in the research where practitioners had assisted with daily living tasks, or undertaken leisure pursuits with and valued by the individual, in order to build up a trusting relationship. This had resulted in the person accepting help both from the practitioner concerned but also from other professionals, such as care workers, a general practitioner 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"*. Thus, consideration should be given to who might be best placed to secure engagement. Some agencies/professionals, for instance, may be perceived as less intimidating or threatening than others.

Effective engagement and intervention is also based on a willingness to express concerned curiosity and honesty-based authority where necessary, for example when loss of tenancy is a possibility, or a threshold for environmental health action has been reached. It is 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 those circumstances. This means:

- recognising the influence of a person's history and the challenge of dealing with the consequences of that today
- understanding the need to balance respect for private life with a duty of care
- offering a range of possible services in order to respond holistically to the individual.

Seeing the person holistically may mean 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, requires both confidence and skills.

Therefore, effective engagement involves:

- authenticity of approach
- finding the right tone and pace
- respectful challenge of deflection and rejection.

Engagement must also be informed by how the individual understands their situation. Self-neglect can be both a cause and a result of mental or physical ill-health, and of particular experiences of social and familial relationships. It can have a significant emotional impact, such as demoralisation and seclusion through shame and embarrassment. Self-neglect of one's person may be rooted in different standards, an inability to self-care, demotivation caused by personal circumstances or other preoccupations being given a higher priority. Self-neglect of one's surroundings may be rooted in mental or physical ill-health, the influence of the past or, as in the case of particular types of hoarding, may be seen as having a value. Effective engagement includes, therefore, encouraging reflection.

Equally, willingness to engage may be prompted by a particular incident, such as the discovery of infestation, or by a particular practitioner who is seen as unintrusive, respectful and willing to listen and spend time. People may have found services difficult to access, perhaps because referral routes have been unclear or eligibility criteria too tightly drawn, or they may have been given little choice by an agency with statutory powers. Effective engagement sometimes involves, therefore, finding and reinforcing the motivator for change.

Staffing and support

Not everyone may be able to do self-neglect work. It requires confidence, persistence and resilience, sometimes a willingness to engage in practical but unpleasant tasks, sometimes assertive outreach, sometimes to ask what one person has described as '*care-frontational questions*'. So, greater account should be taken in the allocation of such work of practitioners' special interests and skills. Moreover, the work can prove emotional, challenging, anxiety-provoking and frustrating. This requires recognition and containment so supervision, which includes checking out the practitioner's own emotional and physical wellbeing, and health and safety, is essential. It enables practitioners to reflect, to talk through cases and the dilemmas they present, and to

explore possible innovative ways to engage and practise. The support of team and multi-agency colleagues is important too, for sharing ideas and debriefing.

Capacity

The complexities surrounding mental capacity exercised managers greatly; whether or not a self-neglecting adult had capacity was '*that critical point decision*'. Case file audits, observed practice and commissioned SCRs reveal that mental capacity assessments remain a difficult area for people to become and feel competent in, the more so if they are not called upon to complete them regularly. The rigour and thoroughness of capacity assessments are variable, with some managers having developed toolkits or facilitated access to specialists to raise consistency.

Finding that someone has capacity to take particular decisions can lead professionals to conclude that nothing can be done, because people have a right to take unwise decisions, even when those decisions impact on other people and even when particular legal mandates might permit intervention. Put another way, a finding of capacity can act as a block to the consideration of other options and lead to premature case closure. This concern has also been highlighted as a practice shortcoming in self-neglect SCRs (Braye et al, 2015c). Concerns should therefore be expressed about the blanket statement 'they have got capacity' when it is unclear to what decision this applies.

Managers should seek 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 has learnt 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, is crucial to the unfolding of the subsequent care pathway.

Thus, personalisation does involve choice and control, 'to enable a person to live as independently as possible', but does not mean failing to discuss risks and how to keep people safe. Nor should 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 reaches a decision to refuse particular interventions, such as medical care. Put another way, personalisation, positioning the individual as expert, should not erode the professionals' ability to express their knowledge and use their skills authoritatively. The question of capacity is more effectively handled when professionals are clear about the impact of values, such as personalisation and respect for autonomy, on how situations are seen and options envisaged. Equally crucial is clarity about which legal options are available in what situations.

Closely connected with capacity is the question of whether an individual has consented to a particular intervention and, if consent has been secured on one occasion, whether it needs to be confirmed on each subsequent visit. Workers will 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, they

have 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.

Legal literacy

Practitioners and managers too can find the law daunting in its complexity (Pinkney et al, 2008; Preston-Shoot and McKimm, 2012). Managers may themselves be uncertain about the available legal rules, such that access to lawyers and regular legal updates are advisable.

Although legal mandates have their place among interventions in cases of self-neglect, should be considered and may indeed be very useful, they may offer short-term fixes rather than longer-term solutions. The key challenge is appropriate use of the law rather than thinking of it either as the 'first' or 'last' resort. Thus, focusing on relationships is as crucial as legal rules, and being clear what standards practice is aiming for. This may be defined in various ways but includes putting the person 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 includes being clear what 'good' looks like and ensuring that documentation to support decision making in a case is sound. This harks back to underpinning principles for social work practice and to wanting to humanise the process by person-centred practice, which includes opening up issues with people and exploring the choices they are making.

Effective interventions

Positive interventions *as described by people who use services* are practical, such as advice about welfare benefits or support with cleaning, and encouraging and sensitive rather than overly directive, which can prompt resistance. They are person-centred, seeing beyond the manifestation of self-neglect and conveying a genuine sense of understanding, caring, desire to help and reliability. Practitioners who do not give up too readily are appreciated because, as people who use services recognise, it can take time to find the right moment for accepting help. Some people appreciate information about available services, provision of sufficient mental health counselling or therapy, and meaningful group activity.

Positive interventions *as described by practitioners* parallel and extend those described by people who use services. Depending on case circumstances, they may include:

- forms of monitoring
- fire risk minimisation
- safe drinking schemes
- adaptations and repairs
- emergency respite care
- hospital admission
- deep cleaning

- making the person's environment safe
- removal of hoarded material
- care packages
- support with bills
- counselling or therapy
- change of accommodation
- use of family and social connections
- statutory enforced action.

Components of effective interventions with adults who self-neglect include their full involvement where possible in discussion of desired outcomes, and the importance of time and of flexible organisational structures rather than the imposition of strict rules about time allocations and case holding. Equally crucial appears to be continuity of relationship rather than transfer of cases at fixed points of time, and recognition that this is 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 health care worker rather than social worker, or a volunteer or neighbour. The ability to see the individual holistically and to respond to the whole person is important, where necessary lowering thresholds in order to respond to a person's needs. Agency and individual worker specialisation should not mean that they only focus on what they believe to be within their role and remit.

Convening the system, whether in multi-disciplinary meetings, panel meetings or case conferences, is an effective way of:

- reviewing the risks
- identifying how single agencies have been approaching the case
- exploring legal and other options open to partners
- coordinating action.

Whatever is decided upon requires accurate recording (with reasons for what is decided to be within and out of scope) and dissemination, and then active follow-up and review. Where a self-neglecting adult continues to refuse to engage, active monitoring is more appropriate than case closure and withdrawal, as has also been advised by SCRs (Braye et al, 2015c).

This work, however, requires skilled interviewing and authoritative but respectful challenge, rooted in concerned curiosity. Authoritative interviewing may mean, for example, pointing out the risks to others, such as neighbours, where relevant, and seeking a negotiated settlement. Often key to moving a case forward towards positive outcomes is the strength of inter-agency commitment that can be secured.

Questions for managers to consider when reviewing an organisation's self-neglect policy and practice

How clear are the inter-agency organisational arrangements for responding to cases of self-neglect?

Some local authorities locate strategic oversight, multi-agency arrangements and policy development under a safeguarding umbrella, while referrals are managed within care management teams. Other local authorities allocate complex cases to specialist teams while other referrals go to locality teams. The imperative for managers is to ensure that at a strategic level, self-neglect is recognised. The focus is to ensure ownership of the challenge of working with such cases. Thus:

- Do you have a definition of self-neglect and systems for monitoring the volume and standards of the work undertaken?
- Are you able to assess and challenge how other agencies have engaged with self-neglect?
- Are you clear where self-neglect policy and practice sit, strategically and operationally?
- How are mental capacity and risk assessments monitored?
- Are all relevant legal options considered?

How are the ethical tensions in cases of self-neglect approached by the agencies that surround the team involved with the individual, and by the workers within the team?

This question is about the tension between respecting autonomy and expressing a duty of care. There are arguments that can be deployed between the different imperatives and equally when unpacking such concepts as autonomy (Preston-Shoot and Cornish, 2014). Some agencies and LSABs seek to define in policy and procedures an ultimate paramount principle; others leave it to the relevant professional network to agree a proportionate intervention. Thus:

- How clear is the position of the LSAB and of individual agencies regarding the approach to be taken in cases of self-neglect?
- What mechanisms are provided to enable individual practitioners and professional networks to work through the ethical dilemmas inherent in these cases?
- When risks cannot be mitigated by the practitioners and agencies involved, what principles are foregrounded or privileged?

How is the right support made available to adults who self-neglect?

This question concerns:

- referral pathways
- the knowledge and skills of the workforce
- the guidance that is available to assist practitioners
- the flexibility of thresholds and care management systems
- the systems available to facilitate inter-agency working.

Thus:

- How clear are the referral routes for cases of self-neglect into your organisation?
- How flexible are case management structures and eligibility criteria to enable relationships to be built and engagement secured with people who can be hard to reach?
- What resources are available for early intervention?
- Have you the right staffing and skills mix, for instance social workers skilled in taking lead roles, such as risk assessments, and health and social care practitioners with knowledge, skills and resilience to meet people's needs?
- Are safeguarding, legal and mental capacity specialists available to support staff working with demanding cases?
- What systems are available to enable staff to share their anxieties about cases and to facilitate multi-agency working – panel meetings, case conferences, network meetings, reflection groups?
- What guidance is available, for instance to help staff when people refuse to engage and/or accept services?

What can you draw on to defend standards of practice if challenged?

Self-neglect cases are investigated by the Local Government Ombudsman, courts and coroners and senior managers may be called to account for practice and the management of practice. Thus:

- What protocols and policies can you identify that provide a framework for practice and its management?
- How do you ensure that staff are aware of and understand the framework provided and how do you oversee performance?

Conclusion

This research set out to identify what could be learnt from policies and practices that have produced positive outcomes in self-neglect work, from the perspectives of key groups of stakeholders – practitioners and managers in adult social care and in safeguarding, and people who use services – and to frame it against the background portrayed by the national survey.

Practice in self-neglect work is more successful where practitioners:

- take time to build rapport and a relationship of trust, through persistence, patience and continuity of involvement
- try to ‘find’ the whole person and to understand the meaning of their self-neglect in the context of their life history, rather than just the particular need that might fit into an organisation’s specific role
- work at the individual’s pace, but are able to spot moments of motivation that could facilitate change, even if the steps towards it are small
- ensure that they understand the nature of the individual’s mental capacity in respect of self-care decisions
- are honest, open and transparent about risks and options
- have an in-depth understanding of legal mandates providing options for intervention
- make use of creative and flexible interventions, including family members and community resources where appropriate
- engage in effective multi-agency working to ensure inter-disciplinary and specialist perspectives, and coordination of work towards shared goals.

In turn, the organisational arrangements that best support such work include:

- a clear location for strategic responsibility for self-neglect, often the LSAB
- shared understandings between agencies of how self-neglect might be defined and understood
- clear referral routes
- systems in place to ensure coordination and shared risk management
- data collection on self-neglect referrals, interventions and outcomes
- time allocations that allow for longer-term supportive, relationship-based involvement
- training and practice development around the ethical challenges, legal options and skills involved in working with adults who self-neglect
- supervision systems that both challenge and support practitioners.

The research from which this briefing is derived sought to learn from outcomes in specific cases that could be described as positive in some way, 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 and 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, care, being present, staying alongside and keeping company
- **doing**, in the sense of balancing hands-off and hands-on 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 enforced intervention becomes necessary.

That self-neglect work is difficult is well established; that it can be done has now been evidenced.

How the research was carried out

The research study combined quantitative and qualitative methodologies. A national survey, in which all local authorities in England were invited to participate, was designed to ascertain:

- what data were available on the volume of self-neglect work being carried out by local authorities
- the key challenges in this field of work
- workflow processes and pathways
- guidance and protocols
- the extent of training for staff
- the policy and practice approaches thought to be effective.

Responses were received from 53 local authorities, out of a possible 152 – a response rate of 34.9 per cent.

In-depth interviews were conducted in 10 local authorities with practitioners and managers in adult social care and in safeguarding, and with people who use services, in order to gather differing perspectives on what contributes to effective self-neglect work. In some respects, this approach took the reverse of the serious case review approach – seeking to identify what can be learned from good case outcomes. In total, 42 practitioners, 29 people who use services, 20 managers and two carers were interviewed.

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 find out what policies and procedures within and between agencies could support successful work.

Ethical permission for the study was received from the national Social Care Research Ethics Committee (reference 13/IEC08/0013). The Research Group of the Association of Directors of Adult Social Services (ADASS) also approved the research (approval reference number Rg13-014) and the researchers received permission from senior management within the individual local authorities before contacting managers, practitioners and people who use services.

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Self-neglect policy and practice: research messages for managers

The research on which this briefing is based set out to identify what could be learnt from policies and practices that have produced positive outcomes in self-neglect work, from the perspectives of key groups of stakeholders – practitioners and managers in adult social care and in safeguarding, and people who use services.

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