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# Self-neglect policy and practice: Learning from the frontline and people with lived experience



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 people – practitioners and managers in adult social care and in safeguarding, and people who use services.

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Written by **Suzy Braye, David Orr and Michael Preston-Shoot**

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**Social Care Institute for Excellence**

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sosceles Head Office

One, High Street

Egham TW20 9HJ

[www.scie.org.uk](http://www.scie.org.uk)

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## Summary

The research on which this briefing is based (Braye et al, 2014) 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 people – practitioners and managers in adult social care and in safeguarding, and people who use services.

Service involvement was found to be more successful where it:

- was based on a relationship of trust built over time, at the individual's own pace
- worked to 'find' the whole person and to understand their life history rather than just the particular need that might fit into an organisation's specific role
- took account of the individual's mental capacity to make self-care decisions
- was informed by an in-depth understanding of legal options
- was honest and open about risks and options
- made use of creative and flexible interventions
- drew on effective multi-agency working.

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 of how self-neglect might be defined
- joined-up systems to ensure coordination between agencies
- time allocations that allow for longer-term supportive involvement
- data collection on self-neglect referrals and outcomes
- training and practice development around the ethical challenges, legal options and skills involved in working with adults who self-neglect.

At the heart of self-neglect practice is a complex balance of 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-on and hands-off approaches, seeking the tiny opportunity for agreement, doing things that will make a small difference while negotiating for the bigger things, and deciding with others when the risks are so great that some intervention must take place.

## Introduction

It has become widely recognised in recent years that policy makers and practitioners in health and social care find it hard to know how to respond to self-neglect. Self-neglect can describe a wide range of different situations or behaviours. It might mean that someone is not looking after their own health or personal care. Other times, it might refer to not tidying, cleaning or throwing things away for so long that someone's home environment becomes cluttered or dirty enough to pose risks for their health or safety.

## Defining self-neglect

The definition of self-neglect used in this research was broad and centred 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.

Self-neglect may happen because the person is *unable* to manage to care for themselves or for their home, because they are *unwilling* to do so, or sometimes both. They may have mental capacity to take decisions about their care, or may not. Often the reasons for self-neglect are complex and varied, and it is important that health and social care practitioners pay attention to mental, physical, social *and* environmental factors that may be affecting the situation (Braye et al, 2011).

## Why do difficulties arise in self-neglect work?

In part, it is because the factors that have led to the self-neglect are many and may be deeply rooted. Longstanding and complex problems are not easy to resolve, and social care practitioners are sometimes torn between their duty to care for people and protect them from harm, and the need to respect their choices about how they live (Braye et al, 2013).

## The research evidence to date

Reviews of serious cases in which someone has died or come to serious harm recommend sensitive and holistic assessment, attention and persistence in building up trustful relationships, and good knowledge of law (Braye et al, 2015a). But there is no strong research evidence on what approaches work best, particularly in England. Here, the emphasis in policy (Department of Health, 2000) has been on risks from other people, rather than on self-neglect, and there has been uncertainty within and between organisations over when to become involved in self-neglect, what powers and duties exist, and how best to work together.

Because of these challenges, social care practitioners and managers have called for more knowledge about self-neglect, and guidance on the skills and approaches that provide the best support. In response, the Department of Health set up the research study described in this briefing, to find effective ways of supporting people who find themselves in situations of self-neglect.

This briefing highlights the main findings of the research, which included a national survey of local authorities and in-depth interviews with people who use services, practitioners and managers in adult social care. (Further details of the methods used in this research are available at the end of this briefing.) The briefing is intended for people who use services, carers, non-specialist workers and the general public. Similar briefings are available for managers and health and social care practitioners with a specialist interest (Braye et al 2015b, 2015c). For full details of the project, its findings and conclusions, see Braye et al, 2014.

## The national picture: survey responses

The survey responses confirmed that the majority of local authorities and their partner agencies in safeguarding do not routinely collect information about the amount of self-neglect work being carried out. Without hard information, estimates of how much self-neglect work is being undertaken varied widely. Just over half of the authorities said they had defined self-neglect or given examples of it in guidance or policies; 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 most challenging aspect of self-neglect work was where someone with mental capacity, living in a high-risk situation, 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 on the level of risk that should trigger action. There was recognition that care management systems did not always allow the time and continuity of involvement that could facilitate relationship-based practice.



## The perspectives of people who use services, practitioners and managers: findings from the interviews

### Causes of self-neglect

Practitioners and people who use services thought that self-neglect had a number of different causes. For some, there were links to disability, physical or mental health issues, or alcohol or substance misuse.

Often, practitioners felt that the current self-neglect was rooted in the person's life history, a view sometimes given by the individuals themselves. In these cases, self-neglect might be the result of a past trauma or experience of loss (assault, bereavement or the loss of a valued relationship).

Self-neglect was sometimes seen as a coping mechanism: so, for example, hoarding might be an active way of dealing with experiences and emotions that would otherwise be overwhelming, and giving up the hoarded possessions would leave an unbearable gap. For others, self-neglect arose out of chronically low self-esteem and the person's sense that they were not worth any help and did not deserve to live better.

Still others pointed to their current circumstances as the reason why they were self-neglecting, for example questioning what was the point of trying to self-care when they were homeless or suffering from poor health. Some people in this last group raised the question of whether their situation should really be thought of as 'self'-neglect, or whether their lack of self-care was really a result of previous and ongoing neglect by others, for example providers of housing.

### Accepting help

The person who self-neglected sometimes denied that there was a problem, where practitioners thought that there was. Other times, they accepted that there was a problem, but minimised it, blamed others for it, or regularly promised that they would start dealing with it but did not carry through. Reluctance to acknowledge a need for help, or to accept it, might stem from a sense of pride in being self-reliant and not becoming dependent on service input or on other people, from a need for control, or it might reflect genuinely different standards of self-care, hygiene or orderliness.

### The experience and impact of self-neglect

Interviewees spoke about many different situations where self-neglect played a major part. The stories told were all very different, as were the challenges encountered and the approaches taken in practice. This reflected a general awareness that there is no 'one size fits all' solution to self-neglect; it was recognised that each person's circumstances resulted from their individual history, outlook and the specific mix of issues they were facing.

There is no clear point at which lifestyle patterns become 'self-neglect', and the term can apply to a wide range of behaviour. At one end of the spectrum, individuals sometimes showed an almost total lack of attention to personal hygiene, by not washing or bathing, not changing clothes and bedding or not cutting hair or nails, and there may have been signs of incontinence and soiling. There may have been no food in the person's home and little evidence that they were eating, or the food they consumed might have been mouldy, rotten or composed of left-over scraps. Combined, these factors often led to malnutrition, skin breakdown and pressure sores and dehydration, requiring hospital admission, sometimes on a repeated basis. Neglect of their own health care often made things worse.

A number of people also lived in extremely dirty or infested conditions, which had often built up over many years, during which cleaning had not taken place. Some forms of hoarding presented different problems, with individuals tunnelling on hands and knees through the possessions they had accumulated, clambering over piles of things or living in 'burrows' within their own home.

Yet there were different degrees of self-neglect, and many individuals had lower levels of self-neglect than those just described. Nor did one form of self-neglect necessarily go with another; someone whose home was severely neglected might still show self-care, keeping themselves clean and elegant.

### **The emotional impact of self-neglect**

Self-neglect commonly had a powerful emotional effect on individuals. They told how the sense of worthlessness or narrowing of horizons that self-neglect produces reduced their motivation to improve their lives. Some had been through periods of absolute despair. Many, though not all, were keenly worried about how they would be perceived by other people and some worked hard to try to cover up their self-neglect. This was not only about embarrassment or stigma, but could also reflect (sometimes realistic) fears of eviction, forced clearing of possessions or other coercive measures.

Practitioners could also be personally affected by the demands of self-neglect work, feeling that they had to witness considerable suffering, accept risks to themselves, and cope with their own anxieties and sense of responsibility. Several practitioners described self-neglect work as the hardest thing they did, with repeated disappointments and frustrations. The value of reflection and support through supervision was emphasised, being seen as vital in making a space where they could take a step back and explore possibilities to do with the case. Not all personal impacts, however, were seen as negative; in many respects they were seen as part of the job, and the rewards were also emphasised.

### **Approaches to practice**

Practitioners and people who use services shared a wide range of insights and advice on what makes a positive difference with self-neglect in practice. But the five themes that featured most strongly in the interviews were:

- the importance of relationships
- 'finding' the person

- legal literacy
- creative interventions
- effective multi-agency working.

### **The importance of relationships**

The theme that emerged most consistently was the importance of relationships in securing engagement and achieving interventions that could make a difference.

People in situations of self-neglect differed in how ready they were to agree to input from services, from enthusiastic acceptance to extreme reluctance. Some reported that they had 'already been wondering' about how they could make changes in their lives, sometimes after long periods when they had not been open to help; they agreed that it was vital for practitioners, social care workers or voluntary workers to recognise and seize upon these moments. Timing was key.

Some people experienced difficulty in finding out about and accessing relevant services, and some faced coercive measures such as eviction or environmental health enforcement and so had little choice about service involvement. In many of these situations, they did not necessarily object to the principle of receiving help, but were unsure that they wanted the forms of assistance they thought were on offer. They thought that it might mean 'someone going through my stuff', were worried that it might not be 'how I want it done', or thought that they might incur costs that were not justified. An important message here was that input needed to be 'the right kind'. The issue was one of choice, and respect for the individual's judgements on the most appropriate form of help – even when coercive measures were being taken. The degree to which the person was treated with respect could go a long way in creating a beneficial outcome.

Not all interviewees experienced these concerns when services first became involved; however, if the support given was not sensitive and appropriate, they quickly became an issue. It took skilled and careful efforts from practitioners to lay the groundwork of a constructive relationship when first coming into contact with people in these circumstances, but the interviews repeatedly showed the value of doing so.

Positive relationships took time – often several months or more – to build, and continuity of involvement over a long period of time was sometimes needed to build trust. It was important to build rapport, finding the right tone to use and sometimes overcoming lack of trust left over from previous experiences with services, and to gradually build up a relationship by demonstrating trustworthiness. People who use services emphasised the following as being important components of helping – the practitioner's ability to:

- show humanity
- be reliable
- show empathy
- demonstrate patience
- be honest
- work at the individual's own pace.

Some contrasted this approach with other, less helpful, input that they had received, described with words such as ‘nagging’, ‘bossing’, ‘grating’, ‘criticising’ and ‘pushy’. When practitioner approaches were experienced as overly directive in this way, they were deeply unwelcome; and not only did they make a positive working relationship less likely, but they also sometimes provoked resistance to otherwise constructive suggestions. Interviewees considered 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”*. Practical, hands-on help was valued, as were those moments when workers ‘go that extra mile’.

There was some agreement between the practitioners and managers interviewed that self-neglect practice, because of its reliance on building relationships and engaging in long, slow negotiations, often does not fit with organisational expectations about timescales. Limits to the amount of time allocated to any one case and pressure not to keep cases open were thought to belong with care management models that assumed a neat and predictable relationship between assessment, service provision and closure, and did not rely on longer-term engagement. In some cases, it was necessary to adapt workflows in order to allow the ongoing involvement that would lead to positive outcomes, or to put aside temporarily the normal expectations of timely case closure.

### **‘Finding’ the person**

Everyone thought that it was important to find an approach that enables practitioners to explore and understand the individual’s life history and any possible connections it may have to their current patterns of self-neglect. This not only makes a central contribution to building the relationship, but is also hugely valuable in making an accurate assessment of the issues and working out what kinds of intervention might bear fruit for the person concerned.

The practitioners interviewed were able to talk about the past lives, and the past and present social relations, of the people they worked with in some detail; they went to great lengths to try to understand the context in which the self-neglect was occurring. Both people who use services and practitioners often linked self-neglect to earlier experiences, including:

- living through the Second World War
- being in relationships that were sexually, physically and/or emotionally abusive
- losing valued roles in employment or as a parent.

At other times, self-neglect was a response to a relatively recent change of living conditions or approach to life, and might be a coping mechanism, the reflection of badly damaged self-esteem, or occasionally even an indirect means of communication.

Practitioners noted that self-neglect was sometimes occurring in the context of complex family relationships that took time to understand accurately. This was particularly so when two individuals depended on each other – for example, 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. Some relationships seemed to be bordering on abuse of varying

kinds, but continued alongside or contributed to the self-neglect for complex reasons, sometimes related to the self-esteem of the individual. Other family relationships were supportive and might prevent a situation getting worse; social relationships in the community were also supportive in many cases, though these sometimes verged on exploitative or were focused on activity that was harmful to the person's wellbeing, such as heavy drinking. By exploring these different dynamics, practitioners recognised the nature of self-neglect as an intensely personal experience, with a unique constellation of factors in each individual case.

This was an important tool that helped practitioners to devise individualised interventions, responding to each person's personal life experience, networks, relationships and motivations. Equally powerful were the ways in which practitioners recognised the emotional component of people's current experience of their circumstances, working with the fear, anxiety, embarrassment and shame that were sometimes present. People who use services valued calm and understanding reactions to their self-neglect. Where practitioners normalised the self-neglect, neither dismissing it nor treating it as exceptional, this was valued, in contrast to what could be seen as 'over-reactions'. Some people who use services emphasised their own resilience and determination in coping with the circumstances that had led to self-neglect. They felt that practitioners did not often recognise these qualities, focusing instead on the highly visible signs of neglect, and they valued practitioners who recognised and worked with the strengths they had shown.

### **Legal literacy**

Managers and practitioners agreed that awareness of the legal duties and powers that can apply to self-neglect was of huge importance. The Mental Health Act 1983 and the Mental Capacity Act 2005 were both important, as were environmental and public health measures. Although some cases reached risk levels at which action could be imposed, the strong preference was to seek voluntary solutions. Coercive measures were seen as a last resort, providing limited solutions. This often meant a preference for respectful persuasion over enforcement, and at times the limitations of legal powers had to be explained to other agencies or interested parties who assumed that 'surely something could be done'. In general, it was usually desirable for legal interventions to take place through a coordinated sequencing of actions between agencies, although this was not universal practice.

Mental capacity – the question of whether an impairment or disturbance of mind interfered with an individual's decision-making ability – was frequently found to be a key issue to be grappled with, and was often the starting point for deciding what could and should be done by way of intervention. Practitioner knowledge of legal requirements on mental capacity was therefore an essential underpinning to practice.

Capacity assessments might need to be undertaken by any of a variety of professionals, and can involve prolonged discussion between professionals and repeat visits to the individual. In cases of uncertainty, of time having passed or in changed circumstances, practitioners might need to carry out repeat assessments. Practitioners found that capacity that might change from day to day was difficult to assess. A further challenge was that of identifying whether capacity for small decisions denoted capacity to carry out an overall self-care strategy. Where the person was found not to have capacity,

practitioners might plan a best interests intervention, with careful consideration of a wide range of available options to manage risk.

More generally, the way in which different forms of legislation might link together required skills in weighing different options, and expert advice in complex cases was vital.

### **Creative interventions**

Not surprisingly, given how varied self-neglect is, no 'magic bullet' for what works emerged from the interviews. However, key themes that ran through successful interventions were:

- flexibility (to fit individual circumstances)
- negotiation (of what the individual might tolerate)
- proportionality (to act only to contain risk, rather than to remove it altogether, in a way that preserves respect for autonomy).

By paying due attention to these factors, practitioners managed to find creative and moderately successful ways of helping, although they acknowledged that sometimes they could only reduce harm rather than find an ideal outcome. Sometimes low-key monitoring of wellbeing was the only form of assistance that was acceptable to the individual. This often involved community-based voluntary organisations providing specific services such as visiting, befriending or support in managing finances, but sometimes involved members of the individual's social network. Other harm reduction plans included:

- safe drinking schemes (support for a set level of alcohol consumption)
- fire safety measures (even where risky behaviour such as hoarding continued)
- adaptations and repairs in the home.

Such approaches respected the legal right of people with mental capacity to have their autonomy respected, while still taking steps to assist with their safety and wellbeing.

There were actions to assist people with daily living that helped to build up the relationships of trust that have already been highlighted as important. These involved, for example, the provision of key items of furniture or white goods such as fridges and microwaves. The latter were particularly useful where insanitary storage or preparation meant that the individual was eating mouldy or rotten food. Ensuring that the individual had medical attention to deal with specific health conditions was another way of building trust while acting to address concerns about wellbeing.

More dramatic steps were sometimes taken. These were sometimes made necessary by a crisis, but at other times resulted from a gradual, patient process of working towards that moment. Respite care or hospital admission might mean that the person left their home for a period; some practitioners and people who use services gave examples of how time away from squalid or neglected surroundings helped them to see how living differently might improve their quality of life and to accept input that they would previously have rejected. Depending on the state of their home and what they

were willing to accept, this might mean moving to a new home, or efforts to improve conditions in their existing accommodation.

Deep cleaning or the removal of hoarded material could lead to drastic transformations in the home; however, these worked best when they were the result of careful negotiation, resulting in the individual's agreement to what was undertaken. Where intervention to clean or clear a property was necessary, securing the individual's engagement in deciding what should stay and what should go often achieved an outcome over which they had more control.

Practitioners recognised that cleaning and/or de-cluttering were unlikely to result in significant change of behaviour if used in isolation; over time, conditions would deteriorate again. It was therefore important to put a plan into place so that change could be maintained. This might take the form of a care package to ensure that help was provided on a regular basis, or the individual's involvement in meaningful activity that could replace but serve the same purpose as their previous lifestyle. For example, people who hoarded were sometimes linked into workshops or groups that made use of the hobbies or collecting passions that had led them to hoard in the first place, thereby finding alternative outlets for their interests. 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.

Support with bills and paperwork was often provided, along with identification of benefits that could be applied for. 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. At times the focus was on prompting the individual to undertake essential self-care tasks.

Continuity of carers, who were then able to build a rapport with the person, was invaluable, because care packages did not always run smoothly. Ongoing negotiation over what was expected and what was permissible by way of care and support was sometimes called for. Practitioners also found that 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.

Some support aimed to address specific mental health conditions or to change the way in which an individual might think about themselves. However, practitioners sometimes felt that meeting more fundamental survival and comfort needs was necessary before motivation to fulfil other potential could be engaged. Some case narratives showed complex patterns of support in which complex care packages were interspersed with voluntary or compulsory hospital or respite care admissions. Here, practitioners needed to be persistent in seeing things through to some kind of resolution, very often acting as the constant anchor:

- negotiating
- coordinating

- reassuring
- containing anxiety from all quarters
- acting as a bridge
- keeping contact
- keeping company.

Where possible and appropriate, practitioners made constructive use of people's family and social connections. They explicitly sought out those who might have a way through to the individual through a friendship or some other status. Working closely with them sometimes enabled change that would not have been likely otherwise. Some people who use services emphasised the benefits that could come from peer support, people who understood the challenges they faced.

Coercive interventions were also sometimes necessary and used, although the perspectives of people who use services showed that directive approaches could sometimes be deeply unwelcome. Practitioners recognised that the cost was high in human terms, and went ahead only with reluctance, when a basic level of existence was threatened or risks to others were extreme. Nevertheless, there were examples of coercive actions that produced positive change when undertaken with honesty and empathy, and as part of an ongoing relationship and care plan.

### **Effective multi-agency working**

Self-neglect work, while often led or coordinated by adult social care, typically involved many agencies and professions. Sometimes cooperation evolved as a result of parallel strands of involvement coming together as the case developed; sometimes it was the result of a deliberate and explicit strategy shaped at the outset or at a point of review. General practitioners were frequently involved; others often mentioned, depending on the needs of the individual, were district nurses, community matrons, psychiatrists and community nurses from mental health services, drug and alcohol services, psychologists, physiotherapists, occupational therapists, community chiropodists and dentists, pharmacists, community physicians, ambulance crew, police, solicitors, advocates, social landlords, voluntary organisations and those working in housing, environmental health, the fire service, welfare benefits and animal welfare. Bringing together a range of professional perspectives to self-neglect work proved to be a powerful tool for more effective practice.

That said, there were obstacles to overcome. Service boundaries could be seen as barriers to securing input; funding responsibility, diagnosis and specialist services' eligibility criteria sometimes determined whether teams got involved or not.

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. Integration resulted in fewer sticking points over eligibility and brought improvements in communication and access to information. Even where there had not been integration, however, self-neglect work could be well coordinated where there was clarity and flexibility around the roles of the practitioners involved, and clear goals were agreed for their involvement.



It proved helpful to take into account that people may respond more positively to one profession than another (for example, a person who uses services might engage with their general practitioner but be reluctant to talk to a social worker), even where this meant a certain amount of role blurring. It was felt important to think through who might be the right person to make an initial approach and be welcomed, or at least tolerated.

Different agencies and professions sometimes adopted different standpoints on the right course of action to take, with some favouring more immediate hands-on intervention and others arguing for a slower approach that worked over the medium term towards agreement. It was beneficial to agree a common approach, ensuring consistency of the messages then received by the individual. If coercive action was to be taken, pre-planning by those involved – for example, the social worker, outreach worker, environmental health officer and the police – was of great value, enabling shared arrangements to be put in place.

Occasionally, multi-agency negotiations were a very demanding experience. However, 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.

### Management perspectives

As already noted, the question of where self-neglect is positioned between different agencies has not been clear-cut. The study found that some, but by no means all, LSABs had assumed responsibility for oversight and policy development. Here LSAB structures and partnerships could be drawn upon, and having a clearly identified body to which managers and safeguarding leads should answer promoted accountability for self-neglect work.

Some local authorities, with other agency partners, have developed policies and procedures for working with adults who self-neglect, underpinned by definitions of self-neglect, sometimes adding specific guidance on hoarding, service refusal and high-risk cases. Formal high-risk management models were seen as offering clear principles and values, a framework for the assessment and management of risk, and guidance on core elements of practice. These policies were sometimes developed across a number of authorities, or even regionally, with the aim of ensuring consistency of response across a wide geographical area. Sign-up from a range of agencies was important, and locating self-neglect within safeguarding structures made this easier. Differing expectations between agencies on confidentiality and consent to intervention were potential obstacles to collaboration, and LSABs provided a forum for debating and developing joint approaches to such ethical challenges. Assigning lead responsibility and key roles among those involved in self-neglect cases was thought vital.

Agreeing policies across agencies, however, did not necessarily guarantee across-the-board implementation, illustrating the need for ongoing work to ensure multi-agency partnership working. The following are factors that can derail policy implementation:

- policy overload

- lack of joined-up systems
- workload demands
- staff turnover
- limited knowledge and understanding of policy intentions.

A focus on workforce development (the provision of training and supervision) and workplace development (attention to how organisational and inter-agency cultures and systems affect practice) is therefore necessary.

Clarifying referral pathways (how cases of self-neglect find their way into and through local authority and other agency settings) was another important component, ensuring that staff from all agencies know where to refer concerns to or how to follow them up. Without an agreed approach between partners, inconsistent responses can deter later referrals if people feel that the work was not taken forward.

The following were found to be useful in encouraging good practice:

- training
- guidance
- learning opportunities (for example, reflective groups, conferences, specialist panels for high-risk cases, audits of referrals and casework)
- access to specialists.

More systematic data collection on referrals, interventions and outcomes would help develop further understanding.

## 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 people – practitioners and managers in adult social care and in safeguarding, and people who use services.

Service involvement is more successful where it:

- is based on a relationship of trust built over time, at the individual's own pace
- works to 'find' the whole person and to understand their life history rather than just the particular need that might fit into an organisation's specific role
- takes account of the individual's mental capacity to make self-care decisions
- is informed by an in-depth understanding of legal options
- was honest and open about risks and options
- makes use of creative and flexible interventions
- draws on effective multi-agency working.

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

- a clear location for strategic responsibility for self-neglect, often the LSAB
- shared understandings of how self-neglect might be defined
- joined-up systems to ensure coordination between agencies
- time allocations that allow for longer-term supportive involvement
- data collection on self-neglect referrals, interventions and outcomes
- training and practice development around the ethical challenges, legal options and skills involved in working with adults who self-neglect.

The research underpinning this briefing (Braye et al, 2014) sought to learn from positive outcomes in specific cases, and from these to find some key indicators of good practice. 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 that underpins 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 opportunity for agreement, doing things that will make a small difference while negotiating for the bigger things, and deciding with others when the risks mean that some intervention must take place.

This research has shown that although self-neglect work is difficult, it can be done.

## How the research study was carried out

This research briefing draws from a longer research report (Braye et al, 2014) where full details of the methods used can be found. The study included a national survey of local authorities in England and in-depth interviews with adult social care managers, practitioners and people who use services. The survey explored the volume of self-neglect work being carried out, the key challenges, training for staff, and 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 10 local authorities the researchers interviewed individually practitioners and managers in adult social care and in safeguarding, and people who use services, in order to gather a range of perspectives on what contributes to effective work in addressing self-neglect. 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 by practitioners. Thus, the intention of the research project was to build an evidence base about good practice to inform policy and practice development.

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: Learning from the frontline and people with lived experience

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 people – practitioners and managers in adult social care and in safeguarding, and people who use services.

**Social Care Institute for Excellence**  
Isosceles Head Office  
One, High Street  
Egham TW20 9HJ

[www.scie.org.uk](http://www.scie.org.uk)