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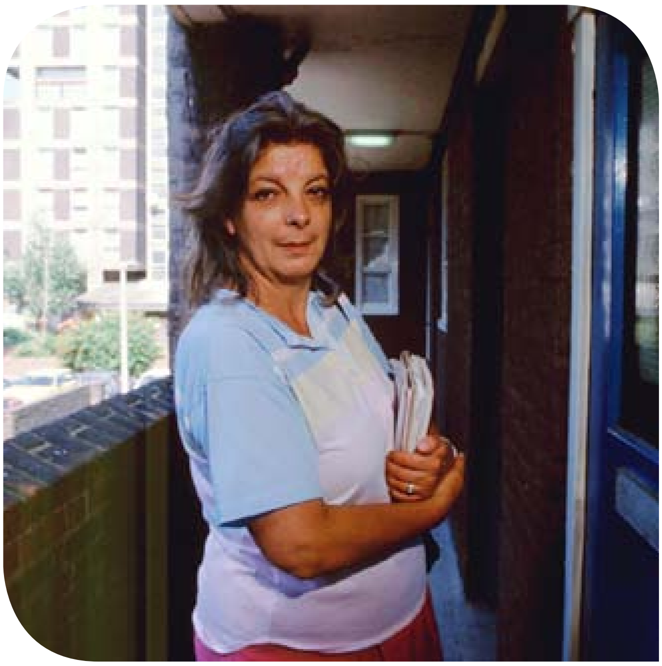
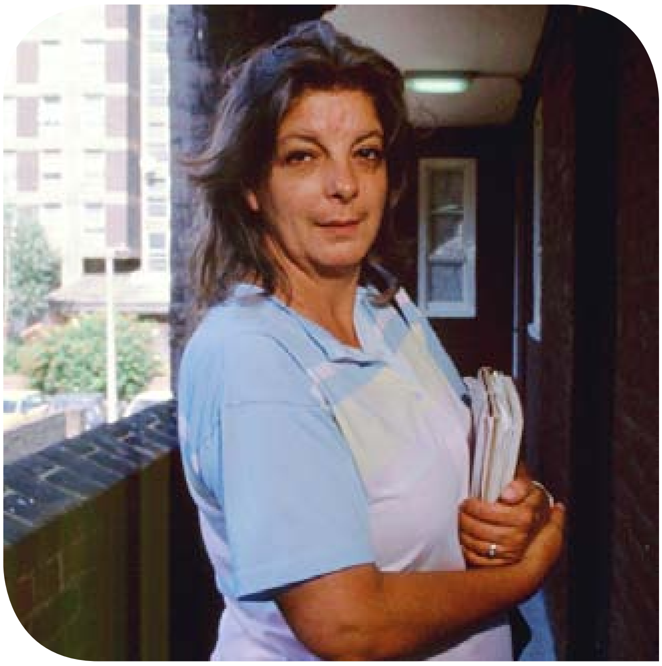
# Self-neglect policy and practice: research messages for practitioners





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, 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, 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 an 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 within workflow patterns 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 enforced intervention becomes necessary.

# Introduction

Self-neglect has emerged as a significant challenge to practitioners and policy makers across a range of agencies. The term covers behaviours that in different ways manifest unwillingness or inability to care for oneself and/or one's environment. For definitional purposes it includes people, either with or without mental capacity, who demonstrate:

- 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.

There is no typical self-neglect picture; each case encompasses a complex and individualised interplay between mental, physical, social and environmental factors. It may be a longstanding pattern or a recent change and be linked to loss, past trauma and/or low self-esteem, with responses shaped by rationalisation, shame or denial. Professional interest, triggered by the level of harm or risk associated with the behaviour, may be at odds with the individual's own perception.

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, in some cases under the overall remit of the LSAB. However, statutory guidance to 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
- care management workflow arrangements
- unclear legal frameworks.

Certain recommendations recur regularly in the literature and in serious case reviews (SCRs), notably the importance of:

- sensitive and comprehensive assessment
- persistence in building up trustful relationships
- good legal literacy
- effective inter-agency communication.

What practitioners and managers have emphasised is their need for knowledge about self-neglect, and skills for effective interventions. Opportunities for inter-professional discussion or decision making and shared risk management are also seen as important, as are organisational arrangements that offer space and time for creative, relationship-based practice. But robust evidence on effective interventions has been lacking, particularly within the English policy context.

The present research briefing for practitioners 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 practitioners and managers in adult social care and in safeguarding, and with people who use services. For full details of the project, its findings and conclusions, see Braye et al (2014). This briefing highlights the salient findings for practitioners. Two further briefings – one for managers 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).

# Findings from the survey responses

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

The aspects of self-neglect work experienced as the most challenging related to situations of very high risk in which someone with mental capacity refuses services. Such situations raised ethical dilemmas in the balance to be struck between respecting autonomy and fulfilling a duty of care. Different agencies sometimes had different expectations of the thresholds for intervention. Further challenges were identifying where lead responsibility for self-neglect lies, who should be involved, and whether it resides within the remit of adult safeguarding or elsewhere.

Common referral routes were into adult social care teams and/or through safeguarding alerts. Joint work was often undertaken with housing or environmental health. A small number of agencies referred to the role of a multi-agency discussion panel in facilitating shared risk assessment and management, shared ownership and coordinated inter-disciplinary involvement. There was recognition that care management systems did not always allow the time and continuity of involvement that could facilitate relationship-based practice.

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

# Findings from the interviews

The interviews with managers, practitioners and people who use services gave a range of insights into self-neglect, and revealed a number of factors that were seen as instrumental in supporting good outcomes in self-neglect work. These are discussed below, first exploring the experience and impact of self-neglect; the approaches to direct practice that emerged as significant are then considered and this is followed by questions of organisational infrastructure.

## The experience and impact of self-neglect

Interviewees spoke about many different situations where self-neglect played a major part. The stories told by practitioners and people who use services were all unique in their own way, 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.

### Diversity of presentation

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, the stories featured individuals who sometimes showed an almost total lack of attention to personal hygiene, by not washing or bathing, not changing clothes and bedding, not cutting hair or nails, or incontinence and soiling. There might be no food in the person’s home and little evidence that they were eating, or the food they consumed might be 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 and sometimes 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 possessions or living in ‘burrows’.

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.

### 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 support, might stem from a sense of pride in being self-reliant and not becoming dependent on service input or on other people, a need for control, or it might reflect genuinely different standards of self-care, hygiene or orderliness.

### Causes of self-neglect

Practitioners and people who use services alike thought that self-neglect had a number of different causes. For some, there were links to physical or mental health issues, disability, 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). It 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, it was just the opposite: the 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.

### The emotional impact of self-neglect

Self-neglect commonly had a powerful emotional effect on the individuals experiencing it. 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 might also reflect (sometimes realistic) fears of eviction, forced clearing 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 – particularly those involving a valued relationship of trust – were also emphasised.

## Approaches to professional practice in self-neglect work

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 the relationship 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. Good timing in finding the moment of motivation, even if it had to be patiently awaited, was felt to be 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 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, 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 – through the provision of small items of houseful equipment or participation in a shared activity – 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 on timescales. Limits to the amount of time allocated to any one case or 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

An approach that enables the practitioner to explore and understand the individual’s life history, and its possible connections to current patterns of self-neglect, was thought to be important. This not only makes a central contribution to building the relationship, but is 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. People who use services and practitioners alike 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, it was a response to a relatively recent change of living conditions or approach to life, a bereavement or a life transition, and might be a coping mechanism, the reflection of badly damaged self-esteem, or occasionally even an indirect means of communication.

Practitioners noted that the 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, or could be mobilised to provide a way forward for the individual; social relationships in the community were also supportive in many cases, though these sometimes verged on being 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, and that practitioners need legal literacy (defined as the synthesis of knowledge, understanding, skills and values that enables practitioners to connect relevant legal rules and policy frameworks with the professional priorities and objectives of ethical practice; Braye et al, 2007). The Mental Health Act 1983 and the Mental Capacity Act 2005 were both significant here, 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, and to involve the individual closely in decisions about, for example, which hoarded materials could be removed. 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 so that support could be provided even while enforced intervention took place, although this was not universal practice.

Mental capacity frequently featured in practitioners’ narratives, and was often the starting point of 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 could take prolonged discussion between professionals and repeat visits to the individual. In cases of uncertainty or time having passed, or in changed circumstances, practitioners might need to carry out repeat assessments. A further challenge was that of identifying whether capacity for small decisions on simple functional tasks denoted capacity to carry out an overall, coordinated self-care strategy. Even where capacity was established, this would not necessarily mean that the professional network withdraws from the individual; attempts to build rapport and relationship could continue.

In many cases, capacity assessments were routinely being evaluated and updated, with approaches that were fine-tuned and multi-disciplinary, although some respondents raised concerns about how thorough and confident practice was in this respect. 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 navigating and weighing different options, and expert advice in complex cases was vital. Legal mandates have their place among interventions in cases of self-neglect, should be considered and may indeed be very useful, but the key challenge is appropriate use of the law rather than thinking of it either as the ‘first’ or ‘last’ resort. Accurate knowledge of the powers and duties available for intervention is crucial, but so too is the recognition that knowing what *could* be done does not mean that it *should* be done, or that the grounds are met in any one individual case; practitioners must consider available legal rules alongside the ethics of intervention and constantly weigh options in the balance.

### Creative interventions

Not surprisingly, given how varied self-neglect is, no ‘magic bullet’ for what works emerged from the accounts. However, key themes that run through the 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 help with daily living, which helped to build up the relationships of trust that have already been highlighted as important. These might involve 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 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 they would previously have rejected. Depending on the state 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 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 clear or clean 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 again deteriorate. 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 ongoing assistance 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, 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, such as enforced cleaning or clearing of hoarded materials, or use of Mental Health Act 1983 powers, 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 more 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 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 social worker, outreach worker, environmental health 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.

## The organisational infrastructure for self-neglect work

Previous research (Braye et al, 2013) revealed a number of challenges for organisations in facilitating self-neglect work. The present study therefore sought to explore further the organisational features that might support good practice in self-neglect work. These emerged as:

- strong inter-agency strategic ownership
- clear referral pathways
- reliable data
- a range of coherent mechanisms for turning strategic commitments into operational reality.

### Strategic ownership

The managers who were interviewed placed great emphasis on the importance of locating self-neglect securely at the strategic level, both within individual agencies and between the key players who had a part to play in assessment or service provision. The complexity of self-neglect entails an equally complex set of inter-agency responses, and shared ownership of the issue is vital. Such ownership provides a strategic home for the development of policies, protocols and practice tools to meet the challenges posed by self-neglect, examples of which had sometimes been developed by the agencies involved in this research.

The mechanisms for inter-agency governance may be the structures and processes provided by the LSAB or may be secured through some parallel inter-agency arrangement. Examples of both models were found, along with hybrid models in which policies and procedures for self-neglect were separate from those used for adult safeguarding more generally, but were nonetheless strategically linked to the LSAB, which provided the accountability route for inter-agency performance and outcomes.

### Referral pathways

Connected to the question of inter-agency ownership was the importance of establishing clear referral pathways for self-neglect, which were well known to staff from all agencies and community groups likely to encounter self-neglect. Such pathways were another aspect of creating an infrastructure that would enable effective responses to be made, whether they included referral through safeguarding routes, through adult social care, or into multi-disciplinary, integrated or specialist teams. Appropriate routes will depend on:

- 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. The best pathway is flexible and responsive to individual need.

Without an agreed approach, the existence of a variety of referral routes leads to inconsistent responses that can deter referrers; equally, there are risks that different thresholds influence whether a particular agency will respond, and that silo working, where a person's needs are not considered holistically, is more likely. Thus, inter-agency agreement on thresholds and pathways is a key element of a robust infrastructure for self-neglect work.

### Data on the volume of self-neglect work being undertaken

Managers were particularly keen to develop ways of capturing data on self-neglect, such as the volume of referrals, and the progress and outcomes of cases. They recognised the challenges of:

- defining such a complex concept as self-neglect in ways that would enable it to be quantified
- agreeing thresholds for inclusion
- securing participation from the wide range of agencies likely to be involved.

Nonetheless, they believed that more accurate data would enable them to quantify the size of the challenge posed by self-neglect, and to make better-informed judgements about:

- policy and procedural matters
- workforce planning
- staff training
- workflow patterns within teams.

Tracking the outcomes of cases can add to the evidence base of effective practice by enabling an evaluation of the outcomes of capacity assessments, risk management plans and individualised multi-agency interventions. Data collection thus enables agencies and the LSAB to have an overview of self-neglect work.

### Turning strategy and infrastructure into practice reality

Strategic agreement across agencies, however, did not necessarily guarantee across-the-board implementation, illustrating the need for ongoing work to turn strategy into operational reality, both within agencies and between agency partners. The following are all factors that can derail policy implementation, as is sometimes shown in evidence from SCRs (Braye et al, 2015c):

- policy overload
- lack of joined-up systems
- workload demands

- resource shortages
- high thresholds
- staff turnover
- limited knowledge and understanding of policy intentions.

Indeed, in some of the agencies involved in the research, it was an SCR that had provoked a concern to engage more proactively with self-neglect and to improve practice by strengthening infrastructure and governance mechanisms. Important ways of realising strategic goals in operational practice were:

- inter-agency collaboration
- training
- supervision and support
- specialist advice
- workflow arrangements within teams.

*Inter-agency collaboration*

Building and maintaining a well-functioning inter-agency network takes time, trust, focus and a willingness to challenge practices. Factors such as co-location, or mechanisms for practitioners to meet together, appear to facilitate joint working. An integrated health and social care system, where it exists, can remove barriers to organisational interaction, for example through staff attending each other's team meetings and joint triage of referrals to enable agreed decisions on responses to referrals.

High-risk management models were in place in some authorities, in some cases specific to self-neglect while in others self-neglect was 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 risk work in all agencies in the LSAB area, including the police, housing, fire and rescue, environmental health, the ambulance service and hospital trusts.

Multi-professional panel meetings or case conferences were key mechanisms for working together, helpful because professionals were in contact with each other to focus on reaching a workable plan with clear duties and responsibilities. Practitioners who had used such a forum to stimulate inter-agency discussion in specific cases had seen some benefit from the opportunity to:

- share and reduce anxiety
- bring the resources of other agencies quickly into play
- determine the best means of engagement

- reduce silo working
- achieve a more coordinated approach.

Such discussion also enabled the ethics of intervention to be debated, achieving some agreement about the balance to be struck between respect for autonomy and a duty of care in each individual case.

*Training*

Where some strategic recognition of self-neglect was in place, training in self-neglect had sometimes been made available. But from the practitioners' perspective, dedicated training was not widespread; practitioners were more likely to have encountered self-neglect tangentially in other training, such as that on mental capacity, or to have transferred their learning from other contexts. Where training on specific aspects of self-neglect had been experienced, it had sometimes caused deep reflection, and had a powerful influence on how practitioners approached their practice.

The evidence from this and previous research (Braye et al, 2013) suggests that more attention could be paid in practice development programmes to the ethical challenges, legal options and communication skills involved in working with adults who self-neglect. Topics to cover 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 multi-agency, built around case studies that facilitate exploration and reflection.

*Supervision and support*

Self-neglect work requires confidence, persistence, patience and resilience, sometimes a willingness to engage in practical but unpleasant tasks, sometimes assertive outreach, sometimes asking what one respondent described as *'care-frontational questions'.* The personal, emotional impact for practitioners of working with self-neglect was very apparent. Engaging with sadness, despair, loss and resignation, and the poignancy of people's attempts to deal with such feelings, is deeply moving, as it is witnessing what is perceived as the loss of dignity that accompanies self-neglect. Feeling helpless yet responsible is a very uncomfortable place to be, and practitioners' experiences indicate the need for robust supervision and support mechanisms to be in place.

*Specialist advice*

Access to specialist advice is also an important component of a safe practice environment. Respondents commonly valued advice on the following, especially so when it was hands-on through joint visits, attendance at case conferences, facilitation of case discussion or securing avenues to resources:

- legal powers and duties
- safeguarding
- mental capacity
- deprivation of liberty safeguards
- mental health.

*Workflow arrangements within teams*

Practitioners and managers alike recognised that self-neglect cases do not fit neatly into care management, reablement or personalised budget approaches to workflow, and that rigid expectations on time allocations, patterns of progress and case closure are difficult to meet. Self-neglect work commonly requires time and patience, and even when engagement is secured, sometimes after weeks or months, the negotiation of even small subsequent changes takes time. Thus, flexibility within organisational approaches to work distribution is crucial for self-neglect cases, including in terms of timeframes for assessment and decision making about thresholds and packages of care, and procedures for closure or transfer of cases between teams. Work allocations need to allow for the continuity of involvement that can enable intervention to be made through a trust-based relationship.

# 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 interdisciplinary 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
- 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 within workflow patterns 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.

In seeking to distil these 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 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 sought to identify policy and practice approaches that have produced positive outcomes in self-neglect work, from the perspectives of all those involved. It combined quantitative and qualitative methods. 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 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 outcomes in specific cases. 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: research messages for practitioners

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, 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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