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Social care responses to self-neglect among older people: an evidence review of what works in practice

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Social care responses to self-neglect among older people: an evidence review of what works in practice

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Summary

We report on a review of the English-language research literature (published 2015-20), which focuses on Adult Social Care responses to self-neglect among older people. We also examine the law and policy context in England provided by the Care Act 2014 and the Mental Capacity Act 2005.

In England, national policy states that self-neglect 'covers a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding' (Care Act 2014 statutory guidance). The topic is in the process of being reshaped as a result of the recognition of hoarding disorder as a discrete psychiatric diagnosis. This development has led to a burgeoning literature specifically focused on hoarding, which we have reviewed separately from this report.

The importance of relationship building and effective multi-agency working were the primary themes identified by our review of the literature.

Building relationships

The literature generally presents the building of good relationships between practitioners and people who self-neglect as the primary 'intervention'. This is likely to involve a sustained engagement on the part of practitioners in order to build rapport and trust. The limited evidence from older people's accounts is suggestive of why this approach might be called for. This evidence includes accounts of traumatic personal experiences from over the course of people's lives, which might be implicated in present behaviour. One attempt to model self-neglect among older people, drawing on interviews with this group, isolated low self-worth, low levels of motivation and lack of agency as key facets.

Practitioner accounts of working with people who self-neglect acknowledged the likely complex psychological derivation of the behaviour and stressed the difficulty of this kind of work. Nurses making home visits to people who self-neglect might experience shock, sadness, guilt, frustration, and helplessness. When seen in terms of safeguarding practice, it was problematic that the person was both the 'abuser' and the 'abused'. Responding to this challenge typically involved establishing rapport, providing practical assistance (e.g., taking food), and working with other agencies. In one study involving care home residents, it was suggested that it may also be necessary to make space for one care worker to deliver tailored care. A kind of pastoral care might be called for, involving the practitioner in challenging the person's negativity directly.

The literature suggests that more concrete interventions work better if they take place against the backdrop of these trusting relationships. There is a potential interplay between negotiated and imposed interventions. These might involve, for example, making the person's environment safe, or supporting the person managing their bills, through to statutory enforced action.

Multi-agency working

It is common for the literature under review to place a high value on multi-agency working because of the complexity self-neglect often involves. Researchers highlight the wide array of agencies that may be engaged and warn of the barriers to good practice, such as lack of joined-up systems (silo working), an ignorance of others' roles, and the lack of a shared language around self-neglect. Facilitators of good practice, on the other hand, are reported to include strategic responsibility being clearly sited, workforce development, and good referral pathways. Analysis of Safeguarding Adults Reviews in the English context has revealed the importance of good attendance at whole system meetings, effective information sharing and good knowledge and use of safeguarding and legal pathways.

In the English context, researchers have suggested that self-neglect work within this broad framework calls for expertise from practitioners, especially in the following areas: legal and ethical; relational (engaging with the person); emotional (the practitioner managing their own stress and anxiety, for example); knowledge (drawing on different sources of evidence); organisational (understanding the multi-agency context); and, decision-making (information sharing and weighing evidence).

In addition to the twin themes of building relationships and multi-agency working, we identified from the US and the Republic of Ireland reports of intensive outpatient primary care programmes, with a multi-disciplinary team (including social workers, senior clinicians and others) focused on self-neglect among older people. We were not able to identify any examples of integrated teams of this kind in the literature from England.

Law and national policy developments

In England, where it appears to the local authority that a person's self-neglect may be giving rise to care and support needs, the authority is under a duty to conduct a needs assessment under the Care Act 2014. In addition, the Act's statutory guidance reclassified self-neglect as a safeguarding concern, although it added: 'It should be noted that self-neglect may not prompt a section 42 [safeguarding] enquiry. An assessment should be made on a case by case basis. A decision on whether a response is required under safeguarding will depend on the adult's ability to protect themselves by controlling their own behaviour. There may come a point when they are no longer able to do this, without external support' (Care Act 2014 statutory guidance). In 2019-20 there were 10,245 concluded section 42 Care Act 2014 enquiries in which self-neglect featured, ranking it at number six of the 11 risk types the annual return to NHS Digital covers.

Ethical questions and mental capacity

A recurring theme in the literature is the difficulty practitioners face in cases where the person has mental capacity with respect to the relevant decisions but is reluctant to alter behaviour that appears to be placing them at risk of harm. The value placed on the autonomy of the individual in these circumstances may be viewed in the light of recent debates on the nature of autonomy and the degree to which the concept should be approached in relational rather than narrowly individualistic terms. In some recent English case law, we see the courts engaging in an attempt to balance the value placed on autonomy with the impulse toward protection.

Conclusion

Among the most striking deficiencies in the evidence identified in this present review is the absence of prospective studies of interventions among self-neglecting older people. A number of leading international researchers share this view. We also found little evidence (of any kind) from England specifically focusing on older people in the field of self-neglect: we report on two such studies within our time-frame.

In light of this, we propose a set of research questions targeted at Adult Social Care in England, split into three areas: identification; safeguarding; and, other operational questions.

The term self-neglect covers a wide range of behaviour and circumstance. Reports of practice in the research literature suggest that starting with relationship building in the context of an optimised multi-agency framework provides a grounding for specific and tailored responses to individual cases.

1. Introduction

This report presents findings from a review of English-language studies (2015-20) focusing on Adult Social Care services for older people at risk of, or experiencing, self-neglect. The review was conducted as part of a study that is examining practice in this field across a number of local authorities in England. In order to inform this work, our account of the international research evidence is supplemented by a consideration of the law and national policy context in England, provided in the main by the Care Act 2014 and the Mental Capacity Act 2005.

The topic of self-neglect in Adult Social Care in England has been heavily influenced by researchers Braye, Orr and Preston-Shoot. Only four of the 18 publications from England included in our review did not involve any of these authors. Their work draws on two strands, against the backdrop of their literature review (Braye et al., 2011), which was commissioned by the Department of Health (DH). First, they undertook a national survey of local authorities together with interviews involving Adult Social Care managers, practitioners, and service users—an important aim here was to identify good practice. This research was conducted in 2013-14 and so refers to the pre-Care Act context, but it fed into work published 2015 onwards, which is the time-frame of our present review. Second is a body of work on Safeguarding Adults Reviews (SARs; building on earlier Serious Case Review work) in which self-neglect was a feature. Rather than evaluate interventions, Preston-Shoot, in particular, has analysed reviews of questionable practice that have been conducted under s.44 Care Act 2014. This calls for SARs to take place when the quality of multi-agency working is a ‘reasonable cause for concern’ in serious cases of abuse or neglect (which includes self-neglect). In broad terms, the resulting literature from these two strands focuses on the value of relationship building between practitioner and service user (and what this entails), and effective multi-agency working (and the barriers to this).

The wider international literature on interventions relating to self-neglect among older people draws mainly on ‘practice wisdom’ (without an equivalent of the English work on SARs). Indeed, we found no prospective studies examining intervention outcomes in self-neglect among older people, with one exception, a US study by Lee et al. (2018), the primary aim of which was to assess whether studies such as randomised controlled trials were feasible for this group. Instead, the literature on interventions is made up of reports of practice, which has not been formally evaluated. These accounts are broadly consistent with Braye et al.’s findings and include much of the experiential literature we found (chiefly from the point of view of practitioners). The international literature also contains a large number of studies on risk factors (completely absent from the English literature)—not directly to do with interventions and so presented in Appendix 2 of this report.

This report starts with a discussion of *Definitions*, which, together with Appendix 1 (on Methods), fleshes out the scope of our review. This leads to the main section, which presents the English-language research evidence on *Management and interventions*. This is followed by a section in which we tighten our focus to discuss *Law and national policy developments* in England, before moving on to *Ethical questions and mental capacity*. The concluding section contains a brief appraisal of the research evidence, a set of suggested outstanding research questions, and a discussion.

2. Definitions

All the reviews and commentaries with an international scope included in this literature review (n=8) comment on the absence of consensus around a definition of self-neglect—Dong (2017), for example, noting that this greatly impedes a systematic understanding of the topic. Often, these expert commentators forgo a definition, preferring to discuss the diversity of approaches they observe. In a paper reporting the validation of a geriatric self-neglect scale, Abrams et al. (2018: e74) drew a sharp contrast between self-neglect, which ‘encompasses multiple manifestations’, and the relatively well-defined phenomenon of hoarding, arguing that, for self-neglect, a ‘parsimonious protocol that balances breadth against depth would constitute an important advance.’

A scope note (in Appendix 1) explains our approach in the light of these definitional challenges, not least our decision to examine the literature with a *specific focus* on hoarding and/or hoarding disorder

separately from this review. This is essentially because of the recognition of hoarding disorder as a discrete diagnosis by the American Psychiatric Association (APA) in 2013 and the growth of a specialist literature. However, while we partition the topic in this way, it is important to stress that for most of the research we examine here hoarding was still explicitly one of the potential manifestations encompassed by the term self-neglect. While a few authors reporting on self-neglect did not mention hoarding, none expressly excluded it. This inclusive approach was the one taken in the *Care and support statutory guidance* which accompanies the Care Act 2014. This guidance which, together with the 2014 Act, governs policy in England in this area, describes self-neglect as covering ‘a wide range of behaviour neglecting to care for one’s personal hygiene, health or surroundings and includes behaviour such as hoarding’ (Department of Health and Social Care (DHSC), 2021: para 14.17). Braye et al. (2017c: 182) refer to the guidance’s ‘expansive definition’, but they incorporate refusal of assistance into the formulation they use (as does Preston-Shoot in his analysis of SARs):

- ‘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.’ Braye et al. (2015b: 2)

These authors expressly include in their definition of self-neglect behaviour that is the result of the person’s inability to care for themselves or their home, or their unwillingness to do these things, or both (Braye et al., 2015b). In not directly addressing this question, the Care Act 2014 statutory guidance implicitly goes along with the Braye et al. perspective here. However, it is worth noting that a range of opinion had been reported in Braye et al. (2011) as to whether people with capacity placed in the unwilling category counted as self-neglecting. Meanwhile, in the US, the National Center on Elder Abuse (n.d.) unambiguously rules out the older person (with capacity) who ‘makes a conscious and voluntary decision to engage in acts that threaten his/her health or safety as a matter of personal choice’ from its definition of self-neglect. We return to this aspect of the topic at the close of this section.

The US is the source of a substantial amount of the literature under review (contributing 22 of the 62 included items). This research commonly quotes the National Center on Elder Abuse (n.d.) definition of self-neglect: ‘the behavior of an elderly person that threatens his/her own health or safety. Self-neglect generally manifests itself in an older person as a refusal or failure to provide himself/herself with adequate food, water, clothing, shelter, personal hygiene, medication (when indicated), and safety precautions.’ In his work, which includes two large-scale epidemiological studies among older people in Chicago, Dong (e.g., 2016: 83) suggests that, in general, elder self-neglect encompasses five different ‘phenotypes’: hoarding, personal hygiene, house in need of repair, unsanitary conditions, and inadequate utilities (heating, etc).

Other definitional aspects

A few further observations, drawing on the literature under review, will help to frame what is to follow in this report.

First, ‘elder self-neglect’ is a well-established category, both within Adult Protective Services (APS) in the US and in US academic commentary (which includes a line of argument that self-neglect might be seen as a geriatric syndrome: Pavlou and Lachs, 2006). An important staging post in the development of research interest in the subject was the publication in the US of the edited international collection, *Self-Neglect in Older Adults* (Day et al., 2017). By contrast, in England, both the statutory guidance and Braye et al. keep their options open here, though in his SAR work Preston-Shoot stratifies his findings by age. Indeed, only two of the included research publications from England focused exclusively on older people: BritainThinks (2017), a report on self-neglect commissioned by Age UK; and Hafford-Letchfield et al. (2020), a small study of older people living in care homes.

Second, an earlier argument made by Snowdon et al. (2012a) as to the classification of ‘severe domestic squalor’ did not feature strongly in the literature we identified. When it did, this was in research focused on hoarding, though one of the aims of Snowdon et al. (2012a) had been to draw

distinctions between the two phenomena—while acknowledging that they did sometimes co-exist. We found a similar state of affairs in relation to Diogenes Syndrome (it came up in the hoarding-focused work), although the term is now less used. Again, the scope note (Appendix 1) discusses this further.

Third, the earlier tendency to refer explicitly to societal norms when setting out definitions in this field (e.g., Shaw and Macmillan, 1957; Gibbons et al., 2006; Snowdon et al., 2012a) does not feature strongly in the recent literature, and not at all in that from England. Exceptions include work from Ireland (Day et al., 2016b; Smyth et al., 2018), Spain (Touza and Prado, 2019), and China (Wu et al., 2020). All these authors use the Gibbons et al. (2006: 16) proposed definition of self-neglect: ‘an inability (intentional or non-intentional) to maintain a socially and culturally accepted standard of self-care, with the potential for serious consequences to the health and wellbeing of the self-neglecters and perhaps even to their community’.

Fourth, a handful of studies came up at the edges of our search. They were characterized by self-neglect not being the primary focus—indeed, sometimes it was not mentioned at all. They consequently raised definitional questions (were the studies presenting competing descriptions or alternative phenomena?), and it is instructive to outline them briefly here, not least because they are illustrative of some of the difficulties faced by researchers in this area.

Wand et al. (2018) conducted an international systematic review of the qualitative literature examining the reasons why older people self-harm. Among the eight included studies (drawn from the US, Canada, Belgium, the UK, Australia and South Korea), five addressed clear attempts at suicide, and three ‘indirect self-harm’ (p.291). In the authors’ own terms, the latter group consisted of cases of self-neglect (not adequately maintaining food, clothing, shelter or medical care or not managing financial affairs); partial or total refusal to eat; and, medication refusal.

In South Africa, Rabie and Klopper (2015) developed nine self-care guidelines from a literature review and a self-care assessment of a sample of older people. They argued that ‘[t]he implementation of the self-care guidelines by the public health sector, professional nurses and older persons will improve the healthcare of older persons at home which will in turn improve their quality of life, [and] reduce unintentional self-neglect’ (p.33).

Cornwell (2016) drew on a large-scale national survey of older adults in the US to examine household disorder, defined as a particular set of physical and ambient household conditions in the dwellings of older people, including general household disrepair, clutter, lack of cleanliness, odour, and noise. Self-neglect and hoarding are not mentioned.

Schafer et al. (2018; 2020) drew on the same survey as Cornwell (2016), remarking: ‘We refer to disorderly household conditions and bodily self-presentation to denote the extent to which household conditions and/or self-presentation depart from societal norms of acceptable order and instead “convey a lack of social cohesion, support, and control in the residential environment”’ (Schafer et al., 2018: 764). They argue for this as a complementary framework to the concepts of squalor and self-neglect.

Hafford-Letchfield et al. (2020: 984) explored the discourse of “‘giving up” on life’ from the perspective of staff caring for older people in four English care homes. According to the authors, this may be a means of ending life through self-neglect or self-harm. Along similar lines, van Wijngaarden et al. (2015: 257) aimed to describe the phenomenon they called ‘life is completed and no longer worth living’ as it was experienced among a group of 25 community-dwelling people, 70 years old and above, in the Netherlands. The researchers speculated, in view of the lack of diagnosed depression in their sample of older people, that they may be exhibiting ‘a profound understanding of personal reality’ suggestive of ‘existential suffering’ (van Wijngaarden et al., 2015: 263).

Unwilling...unable

The research of van Wijngaarden et al. (2015) contrasts instructively with that of Gupta et al. (2017) who considered neurobiological mediators of squalor-dwelling behaviour in the US. Where the Dutch

study relates instances of what might be called ‘settled will’ (with respect to a reluctance to self-care or, indeed, to go on living), the US research reports an example of a kind of radical inability. In this case study, it was hypothesised that damage to a part of a 70-year-old man’s brain associated with the site of feelings of disgust (the insula) was implicated in his squalor-dwelling behaviour—that is, as a result of a pathology he was less able to feel the disgust that others could (Gupta et al., 2017).

Drawing, as we do, on a short five-year publication period, our examples in this section on definitions are presented as illustrative of the wide array of experience covered by the topic of self-neglect, rather than as a comprehensive account. But it seems reasonable to venture that this diversity will have a critical bearing on the nature of the responses to it. Before turning to the research evidence on the responses by Adult Social Care in particular, it is worth staying briefly with questions of ability and willingness. They are never far away where discussions of self-neglect are concerned, and they resurface elsewhere in this report. For example, an inability to carry out certain specified activities of daily living (staying clean, for instance) is central to the determination of a person’s eligibility for care and support under the Care Act 2014. This is discussed in Section 4, on law and policy. Ethical concerns arise where the individual is unwilling to accept help, for whatever reason—practitioners having to consider risk to the person, and also, in some circumstances, risk to others (see Section 5, on ethical questions and mental capacity). And, without seeking to generalize from a single small empirical study, we can see from van Wijngaarden et al.’s (2015) nuanced and plausible characterization that these facets of the topic may not be cut and dried. They may present ambiguously:

“‘Life is completed and no longer worth living’ is an expression of an – often quite desperate – desire that life-as-it-is should stop as soon as possible because of the unbearable burden it embodies. It is difficult to unravel the tangle of inability and unwillingness to connect to one’s actual life. Sometimes it appears to be an active resistance, at other times – even in the same life story – a passive inability. Sometimes it appears as an intertwining of being unwilling and unable, at other times it presents itself more like a continuum: unwillingness seems to shift gradually into inability.’ van Wijngaarden et al. (2015: 260)

With these examples of what self-neglect may encompass in mind, we now report the research evidence we identified that examines Adult Social Care responses to this heterogeneous phenomenon.

3. Management and interventions

After describing the only intervention study we found in our literature search, this section goes on to discuss in turn the twin overarching themes which we identified in this literature, namely *relationship building* and *multi-agency working*. The section closes with reports from three individual programmes tailored to address self-neglect among older people.

The only trial of an intervention we found in self-neglect was a US proof-of-concept study, briefly mentioned in our *Introduction*. This was a 10-month randomised controlled trial that used Vitamin D as a placeholder intervention to establish whether Adult Protective Services (APS)-substantiated self-neglecting older people (n=35; >65 years) could be recruited and retained in such a trial (Lee et al., 2018). Describing the study as ‘[s]etting the stage for future research’ (p.223), Lee et al. reported a 72% retention rate (and increased Vitamin D levels among those allocated to the treatment group). In this context, it is worth mentioning a paper that, while not a trial, did also tend to counter the association of self-neglect with service refusal. Booker et al. (2018) found that 75% of APS-substantiated self-neglecting older people (n=77; mean age: 75 years) indicated satisfaction with APS. Over 80% said they would refer a friend. Unfortunately, this US study did not capture the specific services or interventions being referred to (Booker et al., 2018).

To our knowledge there has been no sequel as yet to the Lee et al. (2018) study. In tracing the first of our two themes, relationship building, the evidence is drawn from qualitative studies focusing on the views of practitioners and managers in social care, and to a lesser extent the views and experiences of service users or people contacted by services.

Building relationships

The literature under review generally presents the building of good relationships between practitioners and people who self-neglect as the primary ‘intervention’, with what might be described as more concrete interventions developing from such relationships. The research by Braye et al. (2014), conducted in 2013-14, involved a survey of all English local authorities (with a 35% response rate), and interviews with managers (n=20), practitioners (n=42) and service users (n=29) across 10 English local authorities. Looking back at this work, the authors reflected that positive approaches, according to both practitioners *and* service users, contained common features:

‘they were flexible, constructed from understanding an individual’s unique circumstances; they required extensive negotiation to establish a degree of consensus, sometimes starting with small steps that could be agreed while waiting longer for the trust that would facilitate more major changes; they focused on risk reduction rather than “symptom” reduction.’ Braye et al. (2017a: 187)

This might involve simply staying in contact over the longer term, or the practitioner offering straightforward pragmatic assistance with ‘items of kitchen equipment, repairs, welfare benefits, help to secure medical appointments’ (Braye et al., 2017a: 187). In their *Key research messages* document for the Social Care Institute for Excellence (SCIE), deriving from the same research, Braye et al. (2015b) spelt out what might be required in any given circumstance:

- ‘to show humanity; be reliable; show empathy; demonstrate patience; be honest; work at the individual’s own pace.’ (p.8)
- “‘Finding” the person [...] Some relationships [in the person’s life] 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.’ (pp.8-9)
- Creative approaches might call for: ‘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) [...] negotiating; coordinating; reassuring; containing anxiety from all quarters; acting as a bridge; keeping contact; keeping company.’ (pp.10-12)

Given the focus on relationships, it is significant that the study succeeded in triangulating in the case of eight ‘matched pairs’ (i.e., the practitioner and service user in the same case were both interviewed) (Braye et al., 2014: 9).

The relational approach was summed up by these researchers in their guidance for *Research in Practice* as a matter of ‘Knowing, Being and Doing’ (Braye et al., 2020: 16). The first referred primarily to knowing the person and their history, but also professional knowledge. Being was a question of ‘[r]espect, empathy, reliability, honesty and care; being present, keeping company, being human’ (p.16). Doing might involve: ‘Hands-off and hands-on balance, building consensus over small steps while negotiating larger ones, deciding when intervention is essential’ (p.16).

The importance of relationships was echoed in the BritainThinks (2017) report of a project commissioned by Age UK. This qualitative study was unusual in the literature from England in that it focused on older people and was successful in recruitment. The study conducted in-home interviews (120 minutes long) with 12 older people either experiencing, or at risk of, self-neglect. They were aged 61-87 years old, most living alone in a mix of urban and rural areas. In addition, there were three 90-minute ‘mini groups’ made up of relatives, neighbours, or friends (called ‘concerned observers’), with five participants in each group. Finally, 17 practitioners, drawn from health, social care and the third sector, attended a day-long workshop. Data from the interviews, the mini groups, and the workshop generated the following guiding principles of effective intervention:

1. Build a relationship and rapport with that person
2. Follow a person-centred approach
3. Identify the key people around the person that you should be working with

4. Effective partnership working
5. Remember your responsibilities and limits regarding your professional practice (BritainThinks, 2017)

From the older person's perspective

One study focused on what Braye et al.'s 'unique circumstances' (above) might be from the older person's point of view. Lien et al. (2016: e195) claimed their US study had the largest sample of data from self-neglecting older adults that had been qualitatively analysed: 69 'cognitively intact' over 65-year-olds, referred from 11 community-based senior services agencies. Seventy-two percent of the participants exhibited self-endangerment through unsafe behaviour, 65% exhibited inattention to environmental hygiene, 49% exhibited inattention to personal hygiene, and 45% had refused some or all indicated services. Interviews elicited nine frequently reported themes, which the researchers sorted into two domains: traumatic personal experiences and maladaptive behaviour patterns.

Traumatic personal experiences (four themes) included:

- psychologically traumatic loss, separation, or abandonment (29%)
- violent victimization, physical trauma, or sexual abuse (19%)
- exposure to war or political violence (9%)
- prolonged mourning (7%)

Maladaptive behaviour patterns (five themes) included:

- significant financial instability (23%)
 - severe lifelong mental illness (16%)
 - mistrust of people or paranoia (13%)
 - distrust and avoidance of the medical establishment (13%)
 - substance abuse or dependence (13%)
- (Lien et al., 2016)

The authors called for an alertness to causes deriving from over the life course and for targeted interventions (Lien et al., 2016). It is easy to see how complex circumstances of the kind reported in this study render problematic the drawing of distinctions between individuals who are unwilling and those who are unable to care for themselves.

The BritainThinks (2017) project already mentioned sought to trace common traits among its 12 older interviewees and generated a triadic model:

1. Low self-worth – a feeling that their life no longer had value or purpose and that they were a burden to others
2. Low levels of motivation – the benefit or value of making changes were thought to be outweighed by the effort (often connected with an unwillingness to ask for or accept help)
3. Lack of agency – a problem worsened by financial problems, being disabled, living in a rural location, lacking skills, and being unable to access appropriate solutions

At the workshop, practitioners wanted to add a fourth facet: not wanting to admit there is a problem, linked to feelings of shame, resignation or pride and a desire to maintain independence (BritainThinks, 2017). These findings fed into the development of the five guiding principles for intervention from this study, listed earlier.

From a workforce perspective

An interview study (Johnson, 2017) of 16 home health nurses in the US sought their perspective on older people who self-neglect and the nurse's role, identifying five themes, with sub-themes:

1. Armour
 - a. It's my normal – clients conducted themselves as if their behaviours were normally accepted practices

- b. Control of territory – clients were described as controlling their territory as part of their armour
 - c. Emotion – displays of emotions, such as anger, were described as one way clients controlled their territory
- 2. Psychological derivation of self-neglect was identified by 14 of the 16 nurses, specifically:
 - a. undiagnosed mental illness
 - b. depression
 - c. dementia
- 3. Seclusion, for a variety of reasons:
 - a. isolation by choice
 - b. isolation by others
 - c. isolation by circumstance
- 4. Lack of conformity with socially accepted self-care conventions. This took the form of a tendency to fail to do the following:
 - a. take medications prescribed
 - b. attend to personal hygiene needs
 - c. consume adequate calories
 - d. attend to the living environment
- 5. Nurse responses included:
 - a. emotional – shock, sadness, guilt, frustration, helplessness
 - b. action – establishing rapport, practical steps (e.g., taking food), working with other agencies (APS etc.)
(Johnson, 2017)

Home health nurses were said to be well placed to detect self-neglect, but levels of education on the topic were poor and implementation of self-neglect screening tools was considered vital (Johnson, 2017).

The need for more training for community nurses was echoed by Day and McCarthy (2015). In this Irish study, a questionnaire designed to assess sources and levels of knowledge about self-neglect was completed by 305 community nurses and 34 social workers. Although both groups had good knowledge of self-neglect, social workers were generally better informed, particularly around policy and legal aspects. The researchers were critical of the fact that findings indicated that the main sources of knowledge for participants related to practice and personal experience rather than empirical research (Day and McCarthy, 2015).

Wu et al. (2020) interviewed 21 nurses from geriatric wards in a Wuhan general hospital in China and developed a three-theme conceptual model based on this workforce's perceptions of older people who self-neglect:

1. The conflict between personal recognition and social judgement. The person might not be aware of, or admit to, being in a state of self-neglect. This contrasted with social and professional judgements that were made about them. Factors involved here were:
 - a. poor health awareness
 - b. cognitive impairment
 - c. depression
2. The choice between current needs and individual beliefs. While the professional might assess the person as self-neglecting, the person might think that their own needs were secondary and choose to go on living in a self-neglecting way. Elements here were:
 - a. low sense of self-worth
 - b. frugality
 - c. 'family-first' values
3. Compromise between insufficient abilities and limited resource. Some people knew their needs and really wanted to take care of themselves, but conditions did not allow. Factors:
 - a. limited mobility
 - b. poor social support
 - c. poor financial conditions
(Wu et al., 2020)

'Family-first' was an instance of a culturally specific aspect of self-neglect. According to the authors, Chinese culture emphasizes the bond between family members, including the connection between generations; older adults often put the needs of their families above their own (Wu et al., 2020). Nurses should take this into account, both in their attempts to encourage the older person to care more for themselves, and in balancing this with an understanding of, and respect for, the values that may underpin the behaviour (Wu et al., 2020).

Band-Winterstein's (2018) interview study, in Israel, drew on the experiences of community health nurses who had at least two years' experience of geriatrics. Strongly associating self-neglect with older people, these nurses reported a struggle to deal 'with extremely difficult and incomprehensible experiences and situations, which evoke a wide range of emotions' (p.976). It was often a challenge for them to treat the person in the face of refusal, which was conceptualised by some of the participants as 'older adults engaging in self-neglect as a refusal to receive care, linked to the wish to end one's life' (p.980). Nurses reported compassion fatigue. And a distinction was drawn with other kinds of elder abuse:

'In the case of victim and abuser, the power relations are straightforward and the nurse identifies with the victim. In the case of self-neglect, however, the older person is simultaneously perceived as both the abuser and the abused. In this complex situation, the need to preserve human dignity and freedom raises questions about proper care. The older adult's wishes must be considered, on the one hand, and measures must be taken to ensure adequate and dignified living conditions, on the other. This leads the nurse to contemplate his or her role.' Band-Winterstein (2018: 978)

The author recommended nurses learn to 'bracket' their preconceptions to help them to engage with the lived experience of the person. Institutionally, nurses required support so that they could openly discuss their feelings about these cases (Band-Winterstein, 2018).

In their exploration of the discourse of 'giving up', which was conducted via focus groups with 33 staff from four care homes for older people in southeast England, Hafford-Letchfield et al. (2020) found evidence of both passive and active social withdrawal, as well as refusal of care. In what was an atypical setting in the context of this review, staff recounted a variety of approaches. Distraction could be used to take the person 'out of themselves'. Some participants spoke of pastoral care, which might involve challenging the person's negativity directly. Intimacy and compassion were engaged. There was acknowledgement that some cases needed to be referred back to managers; it may be necessary to make space for one care worker to deliver tailored care. Peer support might also be encouraged from fellow residents. Practitioners reported particular difficulties in obtaining help from community mental health teams, the researchers noting the challenge of finding mental health services outside of dementia care—for depression, for example. Particularly pertinent to this section's focus on relationship building, the authors warned against the danger of 'institutional preferences for care' taking precedence over candidly addressing the person's views about the end of their life (Hafford-Letchfield et al., 2020: 998).

Finally, to two means of management derived from neither older people themselves nor practitioners but from a 'public forum', to which Udomchaikul et al. (2018) presented their findings about self-neglect among older people in Bangkok (Thailand). These findings emerged from focus group discussions with 17 older adults (60 years and over), eight caregivers/carers, seven community board members, and six nurses in primary care. The primary focus in these discussions was an attempt to delineate self-neglect. In terms of management, participants in the public forum (not clearly described in the paper) suggested, first, that volunteer groups should be called upon to assist and befriend (in light of family being too busy to do this). Secondly, people could find more time to look after older family members if they were able to exit illegal loan arrangements with high interest rates and so not have to work such long hours (Udomchaikul et al., 2018).

Interventions

Conceptually speaking, more concrete interventions discussed by Braye et al. are seen as growing out of a successful relationship between practitioner and service user (assuming such interventions are called for). This may involve recourse to legal remedies (see Appendix 4). Within the trusting relationship that has been built up there is a potential interplay between *negotiated* and *imposed* interventions (Braye et al., 2020):

‘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.’ Braye et al. (2015b: 12)

Unsurprisingly, there was a potential tension here with the service user’s outlook. Positive interventions, according to service users, included: practical help, such as advice about welfare benefits or support with cleaning, and assistance that was encouraging and sensitive rather than overly directive, which could prompt resistance (Braye et al., 2015c). The array of positive interventions described by practitioners in this study included:

- ‘forms of monitoring
 - fire risk minimisation
 - safe drinking schemes
 - adaptations and repairs
 - emergency respite care
 - hospital admission
 - deep cleaning
 - making the person’s environment safe
 - removal of hoarded material
 - care packages
 - support with bills
 - counselling or therapy
 - change of accommodation
 - use of family and social connections
 - statutory enforced action’
- Braye et al. (2015c: 23-24)

Band-Winterstein et al. (2017) interviewed 16 social workers in Israel about their professional responses to self-neglect among older people. Four ‘Intervention Scripts’ (p.198), differentiated according to perceived risk, were described:

1. Immediate threat to life – social worker calls for immediate medical and/or psychogeriatric diagnosis along with legally enforced measures
 2. Potential threat to life – social worker attempts to persuade the older person to accept treatment and/or move out of their home, and attempts to involve family members; seeks psychiatric diagnosis, and brings the case before professional committees
 3. Danger of deterioration in the absence of immediate risk – social worker offers varied means of assistance; negotiates provision of services, including cleaning and/or renovating the home
 4. Environmental nuisance – practitioner works together with public health authorities, warning the person about the use of public health laws
- (Band-Winterstein et al., 2017)

Aside from this risk-determined set of interventions, the authors also identified four different approaches social workers might take with individuals:

1. Clinical-therapeutic – longer term, taking into account a person’s history etc.
 2. Problem focused – targeted and short-term, taking less account of personal history etc.
 3. Mixed and integrated approach – mixture of the first two approaches
 4. Follow-up – remaining on stand-by in some cases
- (Band-Winterstein et al., 2017)

Social workers also argued for a multi-disciplinary approach, raising awareness of self-neglect across society, and appropriate budgeting within social services (Band-Winterstein et al., 2017).

It is to the subject of multi-disciplinary, or multi-agency, approaches to self-neglect that this report now turns.

Multi-agency working

In England, one of the reasons that adult safeguarding is thought to be a good strategic home for actions on self-neglect is that the multi-agency protocols that are integral to safeguarding practice are considered to be a good fit with the kind of complexity self-neglect often involves. This view is endorsed in the Care Act 2014 statutory guidance (DHSC, 2021: para 14.141; Carter, 2016). We discuss the formal inclusion of self-neglect within English adult safeguarding practice in Section 4 of this report. For present purposes, such practice comes to the fore chiefly by way of Michael Preston-Shoot's analysis of a set of Safeguarding Adults Reviews that have focused on the quality of multi-agency working in serious cases involving self-neglect. But it is perhaps worth stressing that regardless of whether or not adult safeguarding is being referred to, it is a commonplace for the literature under review to ascribe a high value to effective multi-agency working because of the nature of self-neglect. While such operational questions are typically not examined in any depth, there follows our account of exceptions to this.

In Mulcahy et al.'s (2017) interview study of social workers (n=11) and nurses (n=76) in Ireland working with older people who self-neglect, once rapport had been established with the person—and with their consent—it was often deemed appropriate to involve an array of agencies. Among those engaged were general practitioners, community psychiatric nurses, social workers, psychiatrists, physiotherapists, occupational therapists, and housing officials. In their expert commentary in the US context, MacLeod and Douthit (2015) also argue for the importance of interdisciplinary approaches to manage the complexity of needs here, in their case emphasizing the usefulness of counselling services in primary care settings and the education of primary care doctors on the topic.

Going into more detail, Braye et al. (2015b) reported that barriers to effective multi-agency working included: policy overload; lack of joined-up systems; workload demands; staff turnover; and, limited knowledge and understanding of policy intentions. Good practice was helped by: strategic responsibility being clearly sited—often the Safeguarding Adults Board (SAB); workforce development; clarifying referral pathways; training; guidance; learning opportunities (for example, reflective groups, conferences, specialist panels for high-risk cases, audits of referrals and casework); and, access to specialists. These findings have since been augmented by Preston-Shoot (2019; 2020b), as outlined below.

In a qualitative study of 11 social workers engaged in self-neglect practice in England, Mason and Evans (2020) identified different kinds of relationship dynamics such practice involved. Though ages of service users were not given, when discussing the professionals with whom the social workers collaborated the authors note:

'The idea that self-neglect is frequently identified in older adults' lives was borne out through the range of gerontology and age-related services mentioned (falls clinics, dementia specialists and old age psychiatry) and frequently social workers would speak about the specialist contributions these services could make alongside social care input.' Mason and Evans (2020: 672)

Overall, Mason and Evans (2020) report the involvement of the following agencies:

- Health (general practitioners, community nurses, mental health services, substance misuse services, gerontology clinics for dementia or falls, paramedics and hospital staff and allied health disciplines, particularly occupational therapy)
- Housing (tenancy support, housing repairs and landlords across the range of housing tenures)
- Voluntary and community care sector (care agencies, meals on wheels, day centres, befriending services, and age-specific national charities)
- Other services, such as the police, pest control and the fire services

The same authors discussed four 'logics', or modes of working, each one potentially arising at different times, depending on circumstance:

- Logic of social work leadership – other practitioners' activity is seen as organised around the social work process
- Logic of joint responsibility – other practitioners' work is seen as distinct and occurs in parallel to social work
- Logic of conflict – other practitioners were perceived as working in adversarial ways
- Logic of proxy – allows for others to act on behalf of social work
(Mason and Evans, 2020)

The PhD thesis by Aspinwall-Roberts (2020, unpublished) is called 'Developing shared understandings of multi-agency working with adults who self-neglect' (it is not limited to older people). Its unique contribution in this context stems from the wide range of agencies she involved (in interviews and/or workshops) in a project that spanned two northern English local authorities:

- Social workers
- Occupational therapists
- Domiciliary care staff
- Physiotherapists
- Psychologist
- Community Nurses
- Fire services
- Homelessness services
- Royal Society for the Prevention of Cruelty to Animals (RSPCA)
- Community Mental Health Nurses
- Housing
- Paramedics
- Age UK advocates
- General practitioners
- Police
- Accident and Emergency consultant
- Environmental Health Officers
(Aspinwall-Roberts, 2020)

Not surprisingly, Aspinwall-Roberts (2020) questions whether service users may experience agency overload as oppressive, particularly if there is no lead contact.

Three main findings from this study, drawing on a mix of group and individual interviews with staff from 17 different professional groups from across the two local authorities (totalling 245 participants), were as follows:

1. On professional roles and responsibilities. Among agencies, she found ignorance of others' roles (and also agencies' own roles). She also found professional 'snobbery' and blurred boundaries (i.e., lack of role definition). Particular manifestations included:
 - a. One 'Housing Officer, educated to degree level and no longer employed by the local authority, felt he was just seen by other agencies as the "rent man". Environmental Health Officers felt they were seen as "the clearance team", qualified mental health professionals as "support workers", paramedics as "ambulance drivers" and so on' (p.219).
 - b. Mental capacity assessments were seen as the preserve of particular groups, such as social workers and paramedics. Aspinwall-Roberts recommends that other professional groups should also be encouraged to see it as part of their role, and that agencies which are opting out of completing mental capacity assessments need to be challenged.
2. A shared language around self-neglect? Aspinwall-Roberts (2020) questions whether, in a newly developing area, there is a shared language among the agencies. She identified a

reluctance to use the word 'squalor', when it might be the case that strong words were required. Participants seemed to be reluctant to talk about offensive smells. In general, social workers seemed comfortable with the term 'lifestyle choice'. Others, such as Community Mental Health Nurses and homelessness workers, were much less happy with the concept and what may flow from this, namely disengagement by Adult Social Care.

3. Consensus and conflict in multi-agency working. Aspinwall-Roberts (2020) describes the field as a potentially high ambiguity / high conflict zone (Matland, 1995)—the former arising out of a lack of national guidance, the latter often driven by conflicting values and ethical perspectives.

Informed by two multi-agency workshops held in each local authority, involving a total of 120 staff from across the agencies, Aspinwall-Roberts (2020) recommends several organisational nuts-and-bolts ways of improving multi-agency working, which overlap with the work of Preston-Shoot (2019; 2020b). Two specific ones were:

- 'A mechanism to protect staff if a person refuses services (makes an unwise decision) – similar to what happens when someone self-discharges from hospital, or refuses to go into hospital with a paramedic.' (Aspinwall-Roberts, 2020: 149)
- 'A care co-ordinator for self-neglect cases, "somebody who gets the whole picture, who is strong enough to hold it together and keep everybody else informed. You need somebody to grasp that nettle": "a port of call, a person you could go to": "they need somebody managing their care because these people have got multi factors going on, they do get lost in the ether, they need care co-ordinators"' (p.149)

Three other points of interest include her observations that the following agencies were undervalued in the managing of self-neglect practice: home care staff; tenancy support workers; and, mental health support workers. Second, as the methodology of her thesis used an Action Research approach, she co-produced a *Short Guide to Working with Complex Self-Neglect Cases* with participating local authorities.

Finally, again as part of the Action Research aspect of this study, each of the four local authority members of the local SAB partnership agreed to keep complex self-neglect cases open for longer than would be usual—where this was warranted. This was to allow the practitioner involved to build up a trusting relationship with the self-neglecting person. Aspinwall-Roberts (2020) suggests that, in some cases, it may be best to have a professional other than a social worker do this longer-term work: the aim was to find the person who the service user trusts and who knows them best. There is no evaluation, as yet, of these interventions in local practice, which formed part of this PhD study.

Safeguarding Adults Review work

Under s.44 Care Act 2014, Safeguarding Adults Boards (SABs) must commission Safeguarding Adults Reviews (SARs) when 'there is reasonable cause for concern about how the SAB, members of it or other persons with relevant functions worked together to safeguard the adult' and the adult has died and the SAB 'knows or suspects that the death resulted from abuse or neglect'. The duty is also triggered where there is the same reasonable cause for concern around joint working, but the adult is still alive, and 'the SAB knows or suspects that the adult has experienced serious abuse or neglect'. As we discuss in Section 4 of this report, post-Care Act, neglect here includes self-neglect. SARs are conducted with a view to learning lessons for future practice (s.44(5) Care Act 2014), rather than apportioning blame. Given their statutory remit, these Reviews have the potential to assist us in understanding what might optimise multi-agency working.

Building on a cumulative series (reported in Braye et al., 2015a; 2015e; Preston-Shoot, 2016; 2017; 2018; 2019), Preston-Shoot (2020b) presented the following breakdown of 246 SARs and Serious Case Reviews (the predecessors of SARs) conducted in England where self-neglect was a factor.

Breakdown of the 246 Reviews by age, where given:

- 76- 23%
- 60-75 25%
- 40-59 22%
- 21-39 4%

(Gender of the 246, where given: Male, 147; Female, 106)

Nature of self-neglect among the 246 Reviews:

- Service refusal 127
- Lack of self-care 148
- Lack of care of person's environment 58
- All three combined 72

(Service refusal and lack of self-care were often combined: Preston-Shoot, 2020b)

When recommendations were addressed to specific agencies, as a percentage of the 246 Reviews:

- Safeguarding Adults Boards 70%
- Adult Social Care 37%
- NHS Trust 26%
- NHS Clinical Commissioning Group 17%
- Housing 11%
- Police 10%
- General Practitioner 9%

These breakdowns are taken from Preston-Shoot (2020b).

A model of good practice

Drawing on his analysis of these Reviews, Preston-Shoot (2019; 2020b) developed a model of good practice in self-neglect work. It was aimed both at informing practitioners and providing SABs and SAR authors with a tool as they reviewed procedures and practice in relation to self-neglect. Sub-divided into four domains, conceptualised as concentric circles with the adult at the centre, the model (in outline) is as follows.

1. The adult

- Making Safeguarding Personal – person's history, wishes etc. 'Concerned curiosity' in face of reluctance to engage
- Autonomy – approach what may appear to be 'lifestyle choices' with care: 'Loss, trauma, shame and fear often lie behind refusals to engage.' (Preston-Shoot, 2020b: 205)
- Assessments – risk, capacity, and needs
- Planning – thorough planning, with regular review
- Family and social context – understanding this; being alert to coercive control
- Advocacy, where appropriate (ss. 67, 68 Care Act 2014)

2. Professional team around the adult

- Countering silo working – avoiding poor communication and co-ordination, mishandling of transitions; importance of lead agency, having a key worker, and good referral pathways
- Whole system meetings – problems include absence of meetings and poor attendance
- Information sharing
- Knowledge and use of safeguarding and legal pathways
- Recording

3. Organisations around the professional team

- Commissioning provision – good management oversight; specialist services
- Working environment – supervision, support, staffing
- Procedural guidance – availability of practice guidance

4. SABs and inter-agency governance

- Managing reviews – SAB oversight
- Effecting change – SAB role in organising workshops etc.

(Preston-Shoot, 2019; 2020b)

The problematic aspects of working with SARs as evidence are well-known—the absence, for instance, of an obligation on SABs to publish their Reviews and the lack of an updated central repository. An instructive point of comparison is provided in these respects by coroners’ Prevention of Future Deaths reports, which in certain ways are analogous to SARs. The website of the Office of the Chief Coroner (2021) functions as a central repository of these, indexed by category; there is, too, a presumption in favour of publication of these reports (Chief Coroner, 2020).

Safeguarding Adults Reviews usually (though not always) are examining cases where a person is thought to have died as a result of abuse or neglect. As evidence, they may exhibit points in common that do not necessarily closely follow the contours of less severe cases—where circumstances are such that an individual’s well-being rather than their life has been at stake. Even so, it is striking just how commonly self-neglect shows up in these Reviews, compared to other forms of abuse and neglect. An examination of SARs that were conducted across England between April 2017 – March 2019 found that among the 231 Reviews the authors analysed, self-neglect constituted the most common type of abuse or neglect, featuring in 45% of the Reviews (Preston-Shoot et al., 2020).

Again, on the question of SARs’ value as evidence, Aspinwall-Roberts (2020) has noted the danger, when considering them, of losing sight of broader societal and economic circumstances that may be implicated in individual cases. There is a risk, in other words, of allowing the criteria and prism of s.44 Care Act 2014, with its emphasis on the quality of joint working, to distract us from the significance of factors such as budget constraints.

Preston-Shoot (2020b) is alive to this danger, noting also, from a similar perspective, that there are some systemic issues that SARs cannot resolve: ‘These include gaps in the law, for example, when working with individuals in the long-term grip of substance misuse, and challenges created by current law, for example, how legislation perceives of mental capacity or permits information-sharing’ (Preston-Shoot, 2020b: 212). He has elsewhere suggested that the legal, policy and financial context makes up a fifth domain within his model (Preston-Shoot, 2020a). Some of the current questions about mental capacity and self-neglect are addressed in Section 5 of this report and are a focus for the study of which this literature review forms a part. Likewise, questions around information sharing between agencies, especially where a person risks harm to themselves (not others) and does not consent to having their information shared, is a point of interest for the present study (see Mitchell, 2016).

Finally, before turning to reports of three specific programmes beyond England aimed at ameliorating self-neglect among older people, we note that alongside Preston-Shoot’s analysis of SARs, Braye et al. (2017c) formulated an ideal skill-set for self-neglect practitioners. They characterized these as a set of seven ‘literacies’ (p.180). Incorporating both the relational imperative and the importance of good joint working, it could be said that these literacies might serve to animate Preston-Shoot’s model of good practice. Expertise, they argue, is needed in the following specific areas: legal and ethical (both discussed further below); relational (engaging with the person); emotional (the practitioner managing their own stress and anxiety, for example); knowledge (drawing on different sources of evidence); organisational (understanding the multi-agency context); and, decision-making (information sharing and weighing evidence) (Braye et al., 2017c).

Reports from three individual programmes

Three individual programmes targeted at self-neglecting older people are reported in the included literature. The first two, in New York (US) and Dublin (Republic of Ireland), are examples of multi-disciplinary teams working in an outpatient setting. The third is a Chicago (US) programme that engages third sector/voluntary bodies to assist the self-neglecting person to age in place.

Diaz Narvaez et al. (2019) reported a case study of an 80-year-old man, Mr. V., who lived alone and had, among other illnesses, end-stage renal disease and dementia. He was assigned to a Geriatrics Preventable Admissions Care Team in New York City. This was an intensive outpatient primary care programme with a multi-disciplinary team including a clinician, a social worker and a care coordinator.

The team discovered that Mr. V's rent was unpaid and his phone was disconnected. He did not open mail and did not understand any paperwork. He was provided with frequent visits and a 24/7 hotline. Medication blister packs helped reduce polypharmacy. The team helped him to organize his mail and pay his bills; transportation was arranged, appointment reminders sent, and home care hours increased. These interventions resulted in a dramatic decrease in his emergency room utilisation and hospitalisations, while he was enrolled.

The researchers concluded: 'The goal of self-neglect management is harm reduction which can be achieved by enrolling patients in intensive primary care programs. Multidisciplinary team approach is key as each member of the team collaborates to focus on a specific area such as medication adherence or home safety to improve outcomes' (Diaz Narvaez et al., 2019: S24).

In Dublin, an Older Persons' Integrated Care Team was set up in 2017 that consisted of two clinical case managers who were senior public health nurses, a consultant geriatrician and registrar, physiotherapist, occupational therapist, medical social worker and clerical support (Smyth et al., 2018). The aim was to join up primary and secondary care for older people with complex conditions, in particular self-neglect. The team used a Comprehensive Geriatric Assessment (the initial assessment being conducted at home) and each case was discussed at a weekly multi-disciplinary meeting.

'Interventions include provision of home care packages, referrals to day hospitals or centres and when necessary liaising with psychiatry of old age and palliative care in the community, as well as to the evolving system of local Safeguarding and Protection Teams.

'Some examples of interventions in our cases of self-neglect included employing Tús workers [Tús is a short-term work placement scheme for unemployed people] to assist with a traffic light sticker system [...], providing gas safety locks and peg memory boards, referrals to Age Action Care & Repair for tradesmen and day centres. The expansion of Integrated Care Teams will provide an important support for the assessment and management of the expected increase in number of self-neglect cases. Meeting the challenge of knowing when to intervene and balancing autonomy and vulnerability present in most cases will be best addressed through the interdisciplinary gerontological knowledge and skills of such interdisciplinary initiatives.' Smyth et al. (2018: 748)

On contacting the lead author, we heard the team was a going concern, but there had been no evaluation. We were not able to identify any examples of integrated teams of this kind in the literature from England and their presence may be a question to pose in the present study.

The Intensive Case Advocacy and Support (ICAS) program in Chicago engaged 10 non-profit organisations to support community living for older people who self-neglect (Dowling and Slover, 2017). ICAS grew out of the Well-Being Task Force (W-BTF, 2003-) for Chicago's older population. The W-BTF was a multi-disciplinary initiative involving, for example, the training of 30,000 field workers (e.g., utility meter readers) in the signs of self-neglect (overgrown yard, etc.) and supplying a telephone number to which they could report suspected cases. ICAS itself 'provides in-home assessment, case advocacy and support, on-going monitoring, and direct assistance for at-risk seniors' (p.215). It states its aims are to establish a trusting relationship, and provide advocacy and advice on available services. ICAS also incorporates a home repair programme.

A self-neglect assessment measure was deployed in the ICAS work in 2011 and 2015 and improvements were found across the six domains of the measure (home environment; physical living conditions; social network; personal endangerment; physical health risk; mental health status), though improvements were not matched with specific intervention types. Practitioners reported that key features of 'success', that tended to be 'small and incremental' (Dowling and Slover, 2017: 225), were:

- Matching clients with appropriate workers (cultural matching etc.)
- Although short term, ICAS encourages multiple contacts (at least every two weeks) to break through resistance

- Flexibility of role – counselling, transportation, money management etc. (not just standard case management)

(Dowling and Slover, 2017)

We touch on these three international programmes again in the discussion that concludes this report. In the next section we shift our focus to the law and policy context for self-neglect practice in Adult Social Care in England.

4. Law and national policy developments

This section summarises recent developments in English law and national policy directly relevant to self-neglect, not least its formal recognition as a concern of adult safeguarding. This significant policy shift took place as adult safeguarding was put on a statutory footing for the first time by the Care Act 2014 (chiefly in ss. 42-47). However, as will become clear, self-neglect's inclusion among the list of recognized types of abuse and neglect in the Act's guidance (DHSC, 2021: para 14.17) was not without complications.

In addition to their safeguarding obligations, local authorities should also address the care and support needs that a self-neglecting individual may have. Under the present statutory scheme, following a needs assessment conducted under s.9 Care Act 2014, local authorities determine eligibility under *The Care and Support (Eligibility Criteria) Regulations 2015*. According to these regulations, three conditions must be met for the needs to be eligible for care and support under the Act. It must be the case that: the needs arise from, or are related to, a physical or mental impairment or illness; as a result of the adult's needs, they are unable to achieve two or more of the specified 'outcomes' listed; and, as a consequence 'there is, or is likely to be, a significant impact on the adult's well-being' (reg. 2(1)). At least three of the 10 specified outcomes listed in these regulations relate to common concerns in self-neglect: managing and maintaining nutrition, maintaining personal hygiene, and maintaining a habitable home environment (reg. 2(2) (a), (b), and (f) respectively). Not only this, but 'protection from abuse and neglect' (which includes self-neglect) is one of the nine areas that relate to an individual's well-being, as this is conceptualised in the Care Act 2014 (in s.1(2)).

The Department of Health elected to keep local authority safeguarding duties separate from this eligibility framework, 'ensuring that there is a quick and appropriate response when the adult is at risk', as the Department put it (DH, 2014c: 22. And see, DHSC, 2021: para 6.55). Before turning to focus on the present role of safeguarding in this topic though, we note the demise of an earlier legislative approach to self-neglect (although not named as such) brought about by the 2014 Act.

Repeal of section 47 National Assistance Act 1948

This provision (*Removal to suitable premises of persons in need of care and attention*) was repealed by s.46 Care Act 2014, principally on human rights grounds (European Convention on Human Rights (ECHR), Art. 5, right to liberty and security; see Law Commission, 2011). It may, though, conceivably remain a point of reference for some specialist practitioners. Although it was little used, at the consultation stage for its proposals for legislative reform the Law Commission devoted significant attention to the implications of repeal because of a minority of consultees who questioned the move (Law Commission, 2011: paras 9.60-9.96). Section 47 enabled the removal of people from their homes, without their consent and on certain conditions (including the authority of a magistrate), where they:

'(a) are suffering from grave chronic disease or, being aged, infirm or physically incapacitated, are living in insanitary conditions, and
(b) are unable to devote to themselves, and are not receiving from other persons, proper care and attention.'

(s.47(1) National Assistance Act 1948)

Inclusion of self-neglect in the Care Act 2014 statutory guidance

Self-neglect was not mentioned in the Care Act 2014 (financial abuse was the only form of abuse or neglect mentioned in the Act itself), but it found its way into the statutory guidance by the following route.

June 2014: The draft Care Act 2014 statutory guidance (DH, 2014a) was put out to public consultation. It contained only one passing mention of self-neglect (in a case study)—this despite the fact that the Law Commission (2011: 120) had recommended that ‘self-harm and neglect’ should be included within the new statutory regime for adult protection/safeguarding.

October 2014: The first edition of the Care Act 2014 statutory guidance (DH, 2014b) newly classified self-neglect among its list of forms of abuse and neglect in the safeguarding portion of the document, and cited Braye et al. (2014). Self-neglect was described as covering ‘a wide range of behaviour neglecting to care for one’s personal hygiene, health or surroundings and includes behaviour such as hoarding’ (DHSC, 2021: para 14.17).

December 2014: The Health and Social Care Information Centre (HSCIC, precursor to NHS Digital) initiated its own consultation on local authority reporting requirements under the new statute.

March 2015: A month before the safeguarding elements of the 2014 Act came into force, the HSCIC (2015: 20) pointed out ‘that it is likely that most self-neglect cases will not be the subject of a Section 42 enquiry’.

10 March 2016: Major revision of Care Act 2014 statutory guidance (the guidance has been subject to multiple minor revisions and was last updated in April 2021, hence our citing of DHSC: 2021). The 2016 edition integrated self-neglect further into the fabric and ethos of the guidance and inserted four important sentences (in para 14.17, quoted below) with respect to whether or not safeguarding is the right route in these cases. The notable points from the 2016 revision are:

- Relating to the duty placed on local authorities to promote well-being by s.1 Care Act 2014: ‘...the concept of wellbeing is very important when responding to someone who self-neglects, where it will be crucial to work alongside the person, understanding how their past experiences influence current behaviour. The duty to promote wellbeing applies equally to those who, for a variety of reasons, may be difficult to engage.’ (DHSC, 2021: para 1.12)
- Relevance of multi-agency working: ‘...safeguarding partnerships can be a positive means of addressing issues of self-neglect. The SAB is a multi-agency group that is the appropriate forum where strategic discussions can take place on dealing with what are often complex and challenging situations for practitioners and managers as well as communities more broadly.’ (DHSC, 2021: para 14.141)
- Safeguarding may not be called for: ‘It should be noted that self-neglect may not prompt a section 42 enquiry. An assessment should be made on a case by case basis. A decision on whether a response is required under safeguarding will depend on the adult’s ability to protect themselves by controlling their own behaviour. There may come a point when they are no longer able to do this, without external support.’ (DHSC, 2021: para 14.17)

The guidance is here emphasizing the importance of assessing the person’s ability to control their behaviour in relation to the risk of harm to themselves. The relevant parts of s.42 Care Act 2014, with which these last remarks should be read, are:

‘42 Enquiry by local authority

(1) This section applies where a local authority has reasonable cause to suspect that an adult in its area (whether or not ordinarily resident there)—

(a) has needs for care and support (whether or not the authority is meeting any of those needs),

(b) is experiencing, or is at risk of, abuse or neglect, and

(c) as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.

(2) The local authority must make (or cause to be made) whatever enquiries it thinks necessary to enable it to decide whether any action should be taken in the adult's case (whether under this Part or otherwise) and, if so, what and by whom.'

Applied to self-neglect this is, at the least, an awkward formulation (compare the approach taken in s.3 Adult Support and Protection (Scotland) Act 2007, which makes express provision for self-harm in the safeguarding context). Indeed, the Department of Health website's own summary of the March 2016 revision observes (albeit *without* statutory force) that it provides:

'...clarification of enquiries under Section 42 of the Act – ordinarily it is not appropriate for people [who] are failing to care for themselves – Section 42 is aimed at those suffering abuse or neglect from a third party' DH (2016)

The appropriate use of s.42 Care Act 2014 (across safeguarding as a whole) has been elucidated in two documents produced by the Local Government Association and the Association of Directors of Adult Social Services in view of ambiguities perceived by some practitioners (Hodson and Lawson, 2019; Spreadbury and Lawson, 2020). While the more recent of these includes a case study where the person was at risk of self-neglect, neither publication goes further into the nature of the decision-making called for in this specific area.

Mindful of the policy development we have described here, a number of the research questions posed in the concluding part of this report are aimed at finding out what the present practice reality is—six years on from the 2014 Act's implementation. Safeguarding data from local authorities, which are collected centrally on an annual basis, give us the broad picture. Initially, prior to 2017-18, self-neglect was one of four risk types that were submitted on a voluntary basis (NHS Digital, 2018). With self-neglect now part of the mandatory return, in 2019-20 there were 10,245 concluded s.42 Care Act 2014 enquiries in which it featured (though the data do not tell us where these enquiries also featured other types of risk). This ranks self-neglect at number six among the 11 risk types the return covers, beneath neglect and acts of omission (65,590), physical abuse (42,340), financial and material abuse (29,180), psychological abuse (28,535), and domestic abuse (10,825) (NHS Digital, 2020). Unfortunately, individual risk types are not broken down according to the age of the person concerned and these data do not, of course, record those cases of self-neglect managed by Adult Social Care wholly outside safeguarding, in care management.

Safeguarding and care management

In light of the 2016 revision, it is worth noting observations made by Braye et al. (2011) in their initial work on self-neglect, a literature review augmented by workshops, interviews and analysis of SAB documents. They reported that, despite the fact that the pre-Care Act adult protection national policy (DH and Home Office, 2000) focused only on third party abuse and neglect, cases of self-neglect were being dealt with through safeguarding procedures in some local authorities in England. This indicates that in the case of some local authorities there has been a continuity, either side of the Care Act 2014's implementation, in the exercising of judgement around whether or not to engage adult safeguarding in self-neglect cases.

What, then, is the relationship between present statutory safeguarding obligations and the rules governing needs assessments (the gateway to care and support under the Act)? Braye et al. (2017c) describe the obligations placed on local authorities to instigate safeguarding enquiries and to conduct needs assessments as two parallel legal duties. As the statutory guidance puts it, in relation to safeguarding cases:

'Where the adult has care and support needs, local authorities must continue to carry out a needs assessment and determine whether they have eligible needs, and if so, how these will be met. The assessment for care and support should run parallel to the safeguarding enquiry

and the enquiry should not disrupt the assessment process or the local authority meeting eligible needs.’ DHSC (2021: para 6.57)

It may be that the person is refusing assistance. Usually, where this extends to a refusal of a needs assessment the local authority’s obligation to carry one out falls away, though pre-Care Act case law would suggest that such refusal should be ‘persistent and unequivocal’ (*R v Kensington & Chelsea RLBC, ex p Kujtim*, 1999: para 32, quoted in Clements, 2019: 78). However, the local authority’s duty to assess remains in place if the person is a safeguarding concern (including self-neglect) or if they lack capacity to refuse the assessment (s.11 Care Act 2014). In the former case, the guidance notes that,

‘local authorities must undertake an assessment so far as possible and document this. They should continue to keep in contact with the adult and carry out an assessment if the adult changes their mind, and asks them to do so.’ DHSC (2021: para 6.20)

The local authority may also have a duty to arrange for an independent advocate to ‘represent and support’ the adult concerned. Assuming there is not already an appropriate person to help in this respect, the duty applies where the adult would otherwise have ‘substantial difficulty’ in taking part, either in a needs assessment or a safeguarding enquiry. These obligations are set out in ss. 67 and 68 Care Act 2014 respectively.

Towards the end of 2016, the arguments for and against engaging safeguarding were aired in *Community Care* following the death of Robert Crane in a fire (Carter, 2016). This article reported the then Adult Social Care Director Adi Cooper as being in favour of self-neglect’s inclusion in safeguarding because of the access that safeguarding afforded to multi-agency protocols. Gary FitzGerald (then CEO of Action on Elder Abuse, now Hourglass) suggested the safeguarding approach was not appropriate where the self-neglect could be seen as a ‘life choice’ made by the person, as opposed to an indication that the person was no longer able to manage—because of a change in circumstances, for example (Carter, 2016). It is worth noting that Hourglass (n.d.), which is a UK-wide pressure group, does not list ‘self-neglect’ as a form of abuse or neglect.

A quote from the US serves to enrich the picture here, suggesting ways in which self-neglect might fit in the wider safeguarding context:

“‘Why is self-neglect of interest to those in the justice system (eg, police, prosecutors, and courts) if it does not involve wrongdoing by a third person? Because it is inextricably linked to other types of elder mistreatment that involve wrongdoing, as demonstrated by the following four points: (1) The line between self-neglect and neglect by others can be murky in terms of when the duty to care and culpability for failing to care for someone else sets in. (2) Self-neglect is believed to be a risk factor for and a consequence of other types of elder abuse. (3) Fears about long-term care too often drive frail older people to stay in environments where they can no longer properly care for themselves or worse. (4) Improving how we identify and respond to elder abuse in many cases also will improve how we identify and respond to elder self-neglect, for example, through better interventions, training, research, and public awareness. Thus, most efforts relating to elder abuse have a direct bearing on self-neglect as well.’ [Connolly, 2008: S245]’, quoted in Bray et al. (2011: 42)

Connolly’s first point can be reinforced in the English context by noting that once the local authority knows about the self-neglect in a particular case, the degree to which it is responsive comes into play. The triggering threshold for a needs assessment under s.9 Care Act 2014 is low. There may come a point where self-neglect and organisational neglect ‘meet’.

Finally, while emerging findings from our present study suggest that one of the ways of triaging cases is according to whether the person is refusing to accept services or not (a risk calculus sending refusal cases toward safeguarding protocols), in some areas it may be that a distinction is drawn according to whether the person has capacity or not. We have heard indications that people lacking capacity with respect to relevant decisions were being directed into care management, and not safeguarding, since

a best interests decision was seen as a relatively simple course of action. It was striking that two respondents in the pre-Care Act context, in Braye et al. (2011: 43; 68), took the opposite position, saying that people lacking capacity would likely be directed into safeguarding. This may be of interest to researchers in terms of approaches possibly changing over time.

The next section reports further on mental capacity but starts with the central ethical question that often arises in self-neglect work.

5. Ethical questions and mental capacity

‘There’s really nothing we can do if they’re in their right frame of mind. I struggled all the way home yesterday trying to decide . . . maybe this is how she wants to live, maybe this is the way she wants to die, maybe this is her choice.’

Home care nurse quoted in a US study by Johnson (2017: 154)

Acknowledgement of the ethical challenge illustrated by these remarks is common in this literature. The value placed on the autonomy of the individual here meant that when home care nurses in this study reported individuals to Adult Protective Services (APS), where the person was assessed as having capacity in respect of the relevant decisions, then APS took the view that the person was:

“in their right mind,” “making conscious choices to live as they do,” and “the clients have the right to make choices for their lives.” Johnson (2017: 154)

Among the international reviews and commentaries included in this review, Dahl et al. (2020), Dong (2017) and Day et al. (2016a) all highlight this topic as a prominent theme. As Day et al. (2016a) put it in their consideration of the ethical aspects of self-neglect practice, two of the most significant deliberations in cases of self-neglect are: determining (a) if the person is competent (i.e., has mental capacity to make the relevant decisions), and (b) if the person is safe to live in these circumstances. Depending on the nature of the self-neglect, a regard may also be had for the safety of others.

Interestingly, there was some evidence that the tension between the value placed on autonomy and the concern for safety inhering in these deliberations played out differently among the participants in Braye et al.’s (2014) research, depending on role:

“The default balance for practitioners overall probably tilted towards autonomy, being prepared to envisage extreme personal deterioration if capacity is present and risks to others are not excessive” [Braye et al., 2014: 193]. In the study interviews, managers were more oriented towards protection as an expression of the duty of care, possibly as a result of their more overt engagement with organisational responsibilities, but this perspective did not necessarily translate to frontline practice.’ Braye et al. (2017b: 324)

Talk of practitioners being prepared to envisage extreme personal deterioration if the person has mental capacity brings to mind the report by the House of Lords Select Committee on the Mental Capacity Act 2005 (MCA) (2014). The Committee found that the presumption of capacity (s.1(2) MCA) was ‘widely misunderstood by those involved in care [...and was...] sometimes used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm’ (para 105). The mental capacity team at 39 Essex Chambers (2021: 5) refer to accounts of practitioners hiding behind the presumption to avoid responsibility for a vulnerable individual, noting that ‘[i]n our experience, this can happen most often in the context of self-neglect where it is unclear whether or not the person has capacity to make decisions.’

Relational autonomy

One way of considering the ethical significance of the MCA here is to view capacity as a gatekeeper for autonomy (Donnelly, 2010; Skowron, 2019). In Camillia Kong’s (2017: 53) words, ‘mental capacity effectively operationalises this concept, functioning as the “gatekeeping device” for individuals’ right of autonomy’. Going on to examine the nature of the concept being operationalised, Kong (2017) joins others in arguing in favour of relational autonomy (drawing especially, in her case, on Meyers,

1989). Commentators here are countering an ‘individualistic’ position that views autonomy as the intrapersonal achievement of the individual. In doing so, they inhabit a range of different perspectives, but they are in general agreement that autonomy cannot be divorced from relational and social conditions. There is an acknowledgement that relationships may threaten an individual’s autonomy; equally, they may enable it (Series, 2015). In this context, Meyers (1989) contributed the notion of ‘autonomy competencies’,

‘defined as a range of socially acquired perceptual, emotional, and reasoning skills needed in constituting an authentic self [...]. Meyers rightly acknowledges that autonomy is more a matter of degree than an either-or scenario, and even the achievement of episodic self-direction will involve the cultivation of [...] autonomy competencies, through interpersonal support and encouragement.’ Kong (2017: 95-96)

In their consideration of the ethics of self-neglect work, we see Braye et al. (2017b) take up similar positions as they push gently against a simplistic stance in the autonomy / protection debate, seeking instead a more nuanced approach. For them, relational autonomy (they cite Nedelsky, 1989) indicates that practitioners should take greater account of the person’s relational and social context, past and present. But more than this, they argue that ‘engaging in dialogue with clients on making decisions need not be seen as impinging on their autonomy, but as supporting it’ (Braye et al., 2017b: 329). They favour what they suggest might be called ‘positive autonomy’ (Braye et al., 2017b: 330; drawing on McDermott, 2011), involving the promotion of attempts by third parties to enhance the person’s autonomy, rather than adherence to a line of non-interference.

We can see how these approaches fit well with Braye et al.’s arguments (described elsewhere in this report) for relationship building to be at the heart of self-neglect work. In terms of practitioner support, Braye et al. (2017b) suggest that supervision and practice discussion is of heightened importance here, and they argue for the value of giving some staff the opportunity to engage with the person over longer periods of time.

Judicial perspectives

Two judgments help in mapping out some more of the territory in this complex area. They form part of the context in which practitioners in self-neglect work make their decisions. The first is an example of the High Court’s use of its inherent jurisdiction in relation to adults. In *Southend-on-Sea Borough Council v Mr Meyers* (2019), the court found that the adult son of Douglas Meyers was exerting an influence on his father that was ‘insidious and pervasive [...] malign in its effect if not in its intention’ (para 41). At the time of this hearing, Mr Meyers (in his late 90s) was living at a care home as the result of an earlier ruling. But prior to this he had been found by the local authority to be living at his home, with his son, in conditions suggestive of both neglect and self-neglect. Citing a ‘dysfunctional relationship between Mr Meyers and his son that serve[d] to occlude his decision-making processes, concerning where and with whom he should live’ (para 45), Hayden J made an order preventing Mr Meyers from living with his son at home, even though Mr Meyers expressed the wish to do so and was assessed as having the mental capacity to make this decision within the parameters of the MCA.

In some ways, the inherent jurisdiction case law in this area exhibits a kinship with the notions of positive autonomy and of autonomy competencies described above. Judges are aiming at ‘enhancing or liberating the autonomy’ of the individual (*DL v A Local Authority & Others*, 2012: para 54), typically where the nature of a relationship is assessed as presenting a significant threat to their self-direction. On the other hand, the jurisdiction is controversial. Commentators have voiced concerns about its discriminatory application to some groups in society, among them older adults (Pritchard-Jones, 2016). The fact that it sits outside a statutory framework renders it unpredictable and associated judgments susceptible to a kind of mission creep (Ruck Keene, 2014). Indeed, the judgment in *Meyers* was strongly criticized in a recent speech by Sir James Munby (2020). Munby, who was responsible for the seminal judgment in this area of law,¹ based his critique on human rights grounds (ECHR: Art. 5;

¹ Re SA (Vulnerable Adult with Capacity: Marriage) [2005] EWHC 2942 (Fam)

and Art. 8, right to respect for private and family life). In particular, he focused on the fact that Hayden J made an order against the ‘victim’ rather than the ‘abuser’ in the relationship; the judgment thereby deviated from the ‘facilitative, rather than dictatorial’ approach approved by the Court of Appeal in the leading inherent jurisdiction case, *DL v A Local Authority & Others* (2012: para 67).

Munby is former President of the Family Division of the High Court, and he chaired the Law Commission as it developed the proposals that led to the Care Act 2014 (Law Commission, 2011). He was, then, instrumental in the repeal of the power of compulsory removal, which we described in Section 4 of this report. In the same recent speech, he broadened his focus, addressing questions of autonomy in the context of self-neglect generally, from a standpoint for which he is well-known:

‘It is a very strong thing to remove someone unwillingly from the house in which they have lived for a long time and which for them is “home.” Some residential placement may be ‘safer’, but if being removed from everything he has known and still wants has the effect that he simply loses the will to live, what ‘good’ is being achieved?’ Munby (2020: 32)

Munby referred to remarks he had made at:

‘the annual conference of the Directors of Adult Social Services in May 2017 (see the Guardian, 10 May 2017). I said, “We ... know that people die of a broken heart ... How long do people last if they are uprooted? A very short time.” I suggested that social workers should resist the desire to “rescue” the elderly from “squalid” dwellings that they nevertheless regarded as their home. I went on:

“Merely demonstrating that if you let that person go on living in that house there is a foreseeable and appreciable risk that one day a neighbour or carer will come in and find them with a broken neck at the bottom of the stairs – is that sufficient justification for making them leave, if it is going to make them thoroughly miserable? It is no good just saying most people would prefer to live longer in nice new accommodation without breaking their neck – some people would not.” Munby (2020: 32)

Where human rights grounds were central for justifying both the repeal of the power of compulsory removal and for his critique of the judgment in *Meyers*, here Munby develops his position, voicing an antipathy to paternalism and its potential effects.

Were an individual to be found to lack capacity in such a context, amongst other things, their ‘past and present wishes and feelings’ and ‘the beliefs and values that would be likely to influence [their] decision if [they] had capacity’ would have to be considered in making a best interests decision under s.4 MCA. The Court of Protection case involving 89-year-old Manuela Sykes was an example of this. Sykes had been diagnosed with dementia and was found to lack capacity with respect to decisions about her residence and care. She was showing signs of severe self-neglect, but this was an instance where, notwithstanding the attendant risks to herself, the Court of Protection ordered a trial period at home, in the light of her past *and present* wish to live there (*Westminster City Council v Manuela Sykes*, 2014).

Cases such as these are typically very fact specific. Nevertheless, given that *Sykes* involved someone lacking capacity to make relevant decisions, whereas *Meyers* was a ruling where the person had mental capacity, the judgments sit in striking counterpoint to each other—especially in the light of the gatekeeper account of mental capacity and autonomy.² In the 2014 case, Manuela Sykes’s ‘belief in the importance of the individual, her desire for freedom and autonomy [were] magnetic factors’ for District Judge Eldergill in his best interests determination (para 10). In the more recent case, the judge found that the court’s order would ‘restrict Mr Meyers’s autonomy only to the degree that [was] necessary to protect him’ (*Southend-on-Sea Borough Council v Mr Meyers*, 2019: para 45).

² Skowron (2019) presents an overarching descriptive account of the relationship between autonomy and mental capacity in the law of England and Wales that addresses the seeming contradictions here.

These cases are illustrative of the present legal landscape in England. They show attempts being made to forge a balance between the value placed on autonomy, with its possible associated risks, and the impulse toward protection, with its potential to resolve into acts of oppressive paternalism.

Other challenges with respect to mental capacity—fluctuating capacity, the impact of serious substance misuse, and the difficulty of making assessments in the face of the cumulative effect of a series of small decisions that may amount to a self-neglecting scenario—did not show strongly in the literature under review. And advocacy in the context of the MCA or ss. 67 and 68 Care Act 2014 was not widely discussed. However, executive capacity and related topics are an ongoing concern in academic commentary.

Executive capacity

Executive capacity is sometimes referred to as a person’s ability to walk the walk, not just talk the talk. The inability of a person to see a particular decision through is commonly described in terms of executive dysfunction, whether that arises developmentally or as a result of brain injury or illness. Professionals face the challenge of assessing, within the parameters of the MCA, an individual’s ability to put decisions into practice (James Lind Alliance, 2018). One recent SAR, involving a 64-year-old man with Korsakoff Syndrome (a chronic memory disorder commonly caused by alcohol misuse), questioned why executive capacity had not been considered by practitioners (Donovan, 2017). In addressing this topic, both Day et al. (2016a) and Preston-Shoot (2017) argue that assessment and evaluation of decision-making capacity might involve the person both articulating a decision and demonstrating the ability to execute it. In general, the work of Aanand Naik remains a touchstone here. Naik et al.’s (2008: 24) discussion of the ‘Articulate → Demonstrate’ approach emphasized the importance of clinicians supplementing assessments of capacity with reports from carers, social care professionals and others familiar with the person in their home environment. Also of interest is ongoing research by Cameron and Codling (2020) who aim to develop practical guidance for social care professionals in this field.

One of the difficulties here, as Cameron and Codling (2020) remind us, is that neither *executive* nor *decisional* capacity, the shorthand terms in common use, are to be found in the MCA Code of Practice (Department for Constitutional Affairs, 2007) or the 2005 Act itself. A further problem, noted by 39 Essex Chambers (2021), is the lack of determinative case law in this area, meaning that observations in this complex area are tentative. One approach involving the person demonstrating the carrying out of decisions did, though, form part of the (non-self-neglect related) judgment in *Kevin King v The Wright Roofing Company Ltd* (2020), where a Multiple Errands Task was used. In Ruck Keene’s (2020) online commentary:

‘the case is of some interest for highlighting the evidence of a neuropsychologist, Dr Carter-Allison, who carried out a clinic based cognitive assessment as part of the claimant’s rehabilitation programme. She reported on 12 August. This included a “multiple errands task” carried out in Bexleyheath town centre by Dr Carter-Allison and a specialist occupational therapist. This test, as Dr Carter-Allison explained in her report, “evaluates the effect of executive function deficits on everyday functioning through a number of real-world tasks” such as shopping and writing down information. Such observational evidence is vital in the assessment of the situation where a person is said to lack capacity because of executive dysfunction, and this reminds us that in such a situation, a final determination can only be reached by combining assessment by interview and assessment by observation’ Ruck Keene (2020)

Observation, as in this case, may be one way of trying to overcome the gap between professional assessment and the person’s real-world engagement in an activity of daily living (the kind of activity typically relevant in self-neglect). This approach is endorsed by the National Institute for Health and Care Excellence (NICE) (2018) guideline on decision-making and mental capacity in relation to executive dysfunction (at para 1.4.19).

In their guidance note on capacity assessments, 39 Essex Chambers (2021: 15) suggest that a key question is whether the person is 'able to use and weigh (or understand) the fact that there is a mismatch between their ability to respond to questions in the abstract and to act when faced by concrete situations'. They advise:

- 'You can legitimately conclude that a person lacks capacity to make a decision if they cannot understand or use/weigh the information, that they cannot implement what they will say that they do in the abstract, or (if relevant) that when needed, they are unable to bring to mind the information needed to implement a decision;
BUT
- You can only reach such a finding where there is clearly documented evidence of repeated mismatch. This means, in consequence, it is very unlikely ever to be right to reach a conclusion that the person lacked capacity for this reason on the basis of one assessment alone.
AND
- If you conclude that the person lacks capacity to make the decision, you must explain how the deficits that you have identified – and documented – relate to the functional tests in the MCA. You need to be able to explain how the deficit you have identified means (even with all practicable support) that the person cannot understand, retain, use and weigh relevant information, or communicate their decision.' 39 Essex Chambers (2021: 15-16)

Of course, for the person to fall within the jurisdiction created by the 2005 Act, the causative nexus must be present: the inability to make the decision in question must be 'because of an impairment of, or a disturbance in the functioning of, the mind or brain' (s.2(1) MCA). And just as the support principle (s.1(3) MCA) is integral to practice here (as always), so cases relating to an inability to see decisions through that fall outside the MCA may still raise care and support concerns under the Care Act 2014. This is of particular significance given that it might be difficult to establish that a person lacks executive capacity.

As an addendum to this section, and moving away from executive capacity, it is worth noting the ongoing interdisciplinary research programme, *Mental Health and Justice* (2021), led from King's College London. It is examining, among other things, the concepts of metacognition and insight in relation to mental capacity. Of particular interest for present purposes, a recent paper from the programme examined the use of the clinical concept of insight in the Court of Protection, identifying a set of cases where 'the "object" of insight or impaired insight pertained specifically to the person's *need for care and support*' (Gurbai et al., 2020: 8, emphasis in original). Such cases have an obvious pertinence to self-neglect—one of the cases the researchers identified related precisely to the risk of self-neglect because of what was seen as the person's lack of insight into his care needs. Taking insight into account (and what it means to do this) bears on the way that mental capacity is understood and assessed in such cases, and what may then follow for the person concerned (Gurbai et al., 2020). One of the proposed outputs from this programme is a set of guidelines for frontline professionals, social workers included, to take further what was said on this topic by the NICE (2018) guideline on decision-making and mental capacity.

6. Concluding observations

In this final section we consider the state of the evidence and suggest a set of research questions for Adult Social Care in England, before closing with a discussion.

Among the most obvious deficiencies in the evidence identified in this present review is the absence of prospective studies of interventions among self-neglecting older people. We found nothing to add in this regard to existing international reviews by leading researchers in this field:

'In light of the rapidly growing aging population and the alarming effect of elder self-neglect, large longitudinal studies are needed to validate the associated risk and protective factors of self-neglect, and rigorously designed experimental investigations (eg, RCTs) are needed to test the best practices for self-neglect intervention and prevention.' Dong (2017: 953)

Following their review of the literature in English (2000-2016), Dahl et al. (2020: 553) concluded: 'Despite the breadth of the search, this review can neither present a new definition of self-neglect nor provide evidence for novel or optimal intervention strategies.' There is, too, a lack of consensus around a validated self-neglect measurement instrument, although there are a number now in existence (Day, 2020; see Appendix 3). We found few accounts of the perspectives of people thought to be self-neglecting. Ethnicity is rarely attended to in this literature, one exception to this being the PINE study in Chicago (Appendix 2). And finally, we found no publications that traced the comparative costs of different approaches to self-neglect among the older population.

Research questions for Adult Social Care in England

There is a dearth of evidence on Adult Social Care responses to self-neglect in England, since the Care Act 2014 came into force, focusing specifically on the over 65s. As we prepared this report, support for this observation came from the National Institute for Health and Care Excellence (NICE, 2021) guideline on safeguarding adults in care homes (which cater predominantly for older people). Following an evidence review, this noted a lack of guidance on indicators of self-neglect and made this the focus of the first of its recommendations for research, asking: 'What are the indicators of self-neglect among care home residents, and what should the responses be?' (p.63).

Other outstanding research questions suggested by the present review are:

Identification

- How well equipped and confident are Adult Social Care practitioners in identifying self-neglect? This includes making distinctions between different forms of self-neglect (for example, squalor and hoarding) and the use of measurement scales.
- What measures are in place to recognize and respond to self-neglect at an early stage? These might include the use of early help hubs and publicity about self-neglect in the broader community.

Safeguarding

- What proportion of self-neglect work involves s.42 Care Act 2014 enquiries?
- When s.42 Care Act 2014 enquiries involving self-neglect are being undertaken, in what proportion of them is self-neglect the only concern (as opposed to it featuring in combination with other forms of abuse or neglect)?
- What factors are taken into account by local authorities when deciding whether to triage cases into safeguarding?
- Does the present statutory and non-statutory guidance provide adequate support in this decision-making?
- In terms of ameliorating the negative impact of self-neglect on the person and lessening associated public health risks, what does safeguarding add?
- How is information sharing managed, within the Caldicott principles (DHSC, 2021: para 14.187) and the legislative framework in England, particularly where the person withholds their consent to having their information shared among agencies?
- Does the duty to supply information in safeguarding (s.45 Care Act 2014) make a substantive difference to the management of self-neglect cases, given the statutory duty to cooperate across Part 1 of the Act (ss. 6 and 7 Care Act 2014)?

Other operational questions

- In view of the evidence around the value of longer time scales in self-neglect work, how are local authorities realising these, if at all?
- What evidence of local variation and local innovative specialism is there in self-neglect work?
- How is executive capacity being approached in local policies and in practice?
- How are local authorities attempting to discharge their duty under ss. 9 and 11 Care Act 2014, in particular where the person is refusing assessment and self-neglect is a concern?

- What evidence is there of the use and efficacy of advocacy (ss. 67 and 68 Care Act 2014), particularly in cases where the person is refusing assistance?
- Given the complexity and emotional challenges reported in self-neglect work, how are practitioners supported and supervised?
- What evidence is there of the existence of integrated teams and their efficacy, for example in the form of health-led short-term intensive interventions?
- What evaluations have been conducted of commissioned services (for example, third sector or private organisations with a focus on self-neglect, or an aspect of it)?
- What evidence is there of effective joint working with agencies which have a different mandate and different powers from Adult Social Care (for example, housing, the fire service or environmental health)?
- And lastly, in the context of the COVID-19 pandemic, have there been any implications for the prevalence of self-neglect of this social upheaval, and for responses to it? What may be the likely impact of more remote consultations with older people by professionals? Will reluctance to accept help be more 'normal' for fear of infection?

Discussion

What are the goals of Adult Social Care practice here? Often, commentators indicate that it is harm reduction and managing risk—especially in the face of a capacious refusal to engage (Diaz Narvaez et al., 2019; Band-Winterstein et al., 2017). It may be a matter 'of risk reduction rather than "symptom" reduction' (Braye et al., 2017a: 187). '[S]uccess' tends to be 'small and incremental' (Dowling and Slover, 2017: 225). *Management* appears to be the preferred term (as opposed to *intervention* or *treatment*) and because the consequences of self-neglect may spill out into the public sphere, this may involve the management of risk extending beyond the person. Though this report has not reviewed the hoarding-focused literature, it will be interesting, given the isolation of hoarding disorder as a psychiatric diagnosis, to observe whether there is a changing emphasis in the goals of practitioners who are addressing this form of self-neglect.

Thinking about self-neglect in the round, the main prerequisite called for by the literature is a sound generic framework that is enabling of specific responses in individual cases. Discovering generalizable interventions that will fit all types of self-neglect is an implausible project. As Dahl et al. (2020) noted in relation to the international literature in English:

'instead of recommending model solutions, the literature was mainly suggesting the need for a person-centered approach delivered by multidisciplinary teams, which would tailor individualized care plans to treat medical conditions, arrange the living environment, and strengthen social support for self-neglecting older persons.' Dahl et al. (2020: 13)

This approach is in keeping with the diversity we observed in the *Definitions* section of this report. It recalls, too, Lauder's (2001) scepticism that a single theory might explain the phenomenon of self-neglect. And, in the English context, it is consistent with the Care Act 2014 statutory guidance. Referring to safeguarding approaches in a case study involving self-neglect and refusal of services, as well as fraud, the guidance remarks:

'We all have different preferences, histories, circumstances and life-styles, so it is unhelpful to prescribe a process that must be followed whenever a concern is raised' DHSC (2021: para 14.14)

Likewise, where decisions about whether or not to refer to adult safeguarding are concerned, this should be on a 'case by case basis' (DHSC, 2021: para 14.17).

If, within the present legislative landscape, the sound generic framework finds *form* through effective multi-agency working—as much of the literature argues—then the primary *content* is supplied through the forging of good relationships between practitioners and those who are seen as self-neglecting. This is at the heart of what Braye et al. (2015d: 21) are describing when they commend to practitioners the watchwords 'knowing, being and doing'.

And not least because of the potential ethical challenges, building rapport might involve longer time scales (Braye et al., 2017b). Open-ended engagements may call for a single well-matched individual retaining contact (Dowling and Slover, 2017; Hafford-Letchfield et al., 2020; Aspinwall-Roberts, 2020). In the statutory guidance case study referred to above, the social worker called in every couple of weeks for almost a year before a decisive move to supported housing was realised (DHSC, 2021: para 14.14). Practical assistance also features strongly in the descriptions across the literature as part of what is involved here. A suite of what Braye et al. (2017c: 180) describe as 'literacies' is required of practitioners, particularly where practical assistance is joined by the use of more intrusive interventions.

To what extent does this approach involve practitioners in counselling? Recent work focusing on social workers by Jenkinson et al. (2020) draws attention to s.8 Care Act 2014, *How to meet needs*, which refers to counselling as a type of social work (s.8(1)(c) Care Act 2014). It is suggested that:

'A counselling type of social work is the use of a professional relationship to help an individual, through listening and talking, to achieve a necessary change in their mind or in their relationships with others to achieve a well-being outcome.' Jenkinson et al. (2020: 5)

In their research, which examined the responses of 169 social workers in adult social services to situations set out in vignettes, the authors found that participants appeared not to recognize this counselling type of social work role. 'Instead, they mostly decided to assess for or provide other forms of care and support, such as care in the home' (Jenkinson et al., 2020: 3). It is a finding that puts in question the degree to which social workers see themselves as the appropriate people to meet needs by way of a substantive intervention such as counselling.

It may be that Adult Social Care is overseeing cases, and enabling, through the range of joint working scenarios described by Mason and Evans (2020), the intervention of other agencies such as housing, environmental health, or the fire service. Commissioned services may be engaged, as might mental health or other health services. It has long been argued that 'integrated working' between health and social care is called for in this field (Shaw and Macmillan, 1957: 828). However, concrete instances of evaluated approaches with older people in England are scarce. The examples of integrated care teams (Smyth et al., 2018; Diaz Narvaez et al., 2019) that provide intensive support for older people who are at risk of self-neglect are suggestive. This may be a model that would fit well with the kind of intervention being examined by the Social Policy Research Unit at the University of York in a study that commenced as this report was in preparation (Newbould et al., 2021). The project aims to enhance the skills of specialist support workers within community mental health services as they engage with older people with poor mental health who are reluctant to accept care. It is an example, in other words, of one specific kind of professional response to older people seen as being at risk of neglecting to take care of themselves.

Appendix 1: Methods

This appendix contains a scope note (which includes a consideration of the limitations of our study), and a report of the search strategy we used, together with a flow diagram showing the management of the results of that strategy.

Scope note

The topic of self-neglect admits many facets and in this note we explain our approach to the literature review in light of this, with particular reference to hoarding and hoarding disorder, but also touching on severe domestic squalor and Diogenes Syndrome. We also explain other decisions we took which bear on the parameters of this review.

The literature search on which the review is based was conducted in September 2020. The aim of the search was to identify and retrieve research literature in the English language that focused on management and interventions by Adult Social Care (and its international equivalents) in respect of self-neglect among older people. While the reach of our search was international, albeit with the language restriction, our start date for publications of 1 January 2015 reflected our interest in recent changes in the English policy context—described in Section 4 of this report—caused by the coming into force of most of the Care Act 2014 on 1 April 2015.

Classificatory questions

The term *self-neglect* is typically understood to encompass a person's lack of self-care and/or their lack of care for their home, this latter potentially leading to domestic squalor and sometimes involving hoarding. This broad umbrella approach is endorsed by the Care Act 2014 statutory guidance (DHSC, 2021: para 14.17) and, as we note in this report's section on *Definitions*, it is an approach generally followed by the academic literature under review.

The American Psychiatric Association (APA) (2013) included **hoarding disorder** in its *Diagnostic and statistical manual of mental disorders (DSM-5)* as a discrete diagnosis for the first time, describing it as the:

'Persistent difficulty discarding or parting with possessions, regardless of their actual value. [...] The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use.'
(APA, 2013)

The World Health Organization (WHO) followed the APA's lead in the 11th revision of its *International Classification of Diseases (ICD)* in 2018, where the description of hoarding disorder begins: 'Hoarding disorder is characterised by accumulation of possessions that results in living spaces becoming cluttered to the point that their use or safety is compromised' (WHO, 2018). The *ICD* is the formal source for standards for disease classification in the English National Health Service, and WHO Member States are scheduled to start reporting using *ICD-11* on 1 January 2022 (WHO, 2018). It is important to stress that not all hoarding behaviour will meet the diagnostic criteria for hoarding disorder. For example, the APA (2013) notes that hoarding behaviour may be as a result of obsessive-compulsive disorder.

In light of the fast-growing published research evidence associated with these developments, we distinguished work published since 2015 that focused on hoarding and hoarding disorder (among older people), to review it separately (see flow diagram below). The fact that we used 'hoarding' as a search term distinguishes our work from that of Braye et al. (2011)—while they incorporated hoarding into their definition of self-neglect, they did not use 'hoarding' as a search term in their literature review. (On the other hand, Braye et al.'s (2011) search, which had a start date of 2000, was not limited to Adult Social Care responses to self-neglect, or to older people.)

The developments described above raise the question as to whether there may be a growing incongruence between hoarding and other kinds of self-neglect. Where, earlier, Braye et al. (2011: v) noted the lack of an 'overarching explanatory model' for self-neglect, the international recognition of

hoarding disorder as a discrete diagnosis is accompanied, in addition to its diagnostic criteria, by growing evidence on its prevalence, its development and course, and its risk and prognostic factors (APA, 2013). Taken together with advances in understanding of its aetiology, these elements set the disorder apart from the other manifestations of self-neglect, not in themselves amenable to clinical diagnosis—although there is a continuing overlap in respect of the public health risks associated with hoarding and some other kinds of self-neglect. Anecdotal accounts of repeated house clearances occurring at intervals speak of management of high-risk cases amounting to the maintenance of a behavioural tendency in the individual concerned. Advances in treatment options might proffer the hope of breaking out of the cycle.

In the *Definitions* section of this report, we refer to **severe domestic squalor**. According to Snowdon et al. (2012b: 11), in their book-length evidence review, this is a description that applies ‘when a person’s home is so unclean, messy and unhygienic that people of similar culture and background would consider extensive clearing and cleaning to be essential’. Writing in the run-up to the publication of *DSM-5*, the authors pointed out that severe domestic squalor ‘does not describe the people; it refers to the living conditions’ (p.2). They suggested making the broad distinction between wet squalor, involving ‘moist or liquid excrement, decayed material, or water spillage or overflow’ (Snowdon et al., 2012c: 181), and dry squalor, involving the ‘disorganised accumulation of dry goods, often including clothing, papers...’ (p.181). And they proposed a working classification, which shows how there *may* be an overlay with hoarding behaviour, though they reported (p.183) that most people who hoard do not live in squalor:

- (1) ‘Dry, neglectful squalor
 - (2) Rubbishy, neglectful squalor
 - (3) Wet, neglectful squalor
 - (4) Dry clutter
 - (5) Dry extensive clutter or hoarding, and
 - (6) Dry, semi-organised hoarding.’
- Snowdon et al. (2012c: 181)

In this literature review, on the rare occasions when severe domestic squalor was the focus of a paper, this was usually presented in tandem with a consideration of hoarding (whether or not this met the diagnostic criteria set out by the APA for hoarding disorder) and so these papers have not been reviewed here.

Finally, a note on **Diogenes Syndrome**. The term was introduced into the self-neglect literature by Clark et al. (1975), writing in *The Lancet*. While commentators have exhibited considerable latitude when using the term since this time, it is commonly associated by them with self-neglect that includes hoarding behaviour. This reflects the findings of the 1975 article, which reported a study from the Department of Geriatric Medicine at Brighton Hospital (Martineau, 2020). Though we searched for the term ‘Diogenes Syndrome’, it was not widely used in the period under review (2015 – mid-2020). Where we did identify papers in which it featured, these we reviewed among the hoarding-focused literature.

In short, while hoarding and hoarding disorder, severe domestic squalor and Diogenes Syndrome are typically included within the umbrella term of self-neglect and hence are usually part of what is being considered in the literature in this review, where these facets were the *express focus* of a publication, we have reviewed it separately.

Other aspects of the review

Our guide age for ‘older’ was 65 years and above. However, unlike in the US and some other countries, ‘elder self-neglect’ is not a well-recognized category in England, meaning that researchers have rarely limited their work to older people. This is the case with the work of Suzy Braye and colleagues and the analysis of SARs by Michael Preston-Shoot. As a result, given our interest in the English context, we relaxed the age criteria in respect of the academic work from England, while remaining mindful of our target population.

Our focus on management and interventions meant that studies focusing on prevalence, causation, and self-neglect outcomes formally fell outside the scope of our search. However, we thought it useful to retain the (generally) large-scale epidemiological studies focusing on older people, which we label 'risk-factor studies', because they bear on the potential detection and prevention of self-neglect. These are in Appendix 2. We have included what we found on self-neglect assessment measures in Appendix 3 for the same reason.

While we have considered law and *national* policy in this report, the study of which this review forms a part is also examining a sample of *local* policy documents from England, and we hope to publish findings from this analysis in due course.

We are aware of two practitioner handbooks produced for the English context, Barnett (2018) and Britten and Whitby (2018), neither of which were available to us electronically. Falling outside our remit because not peer-reviewed, the work of Peter Bates (2020, updated at intervals) is a rich consideration of self-neglect, again in the English context, with a focus on personal hygiene (unusual in this literature). None of these concentrates specifically on older people.

At the time of writing, there is an initiative by the Local Government Association and others in England to improve Adult Social Care responses to people who are homeless. Self-neglect is a significant aspect here, but we have not included this work in the present review since there is an ongoing study on this topic at this research unit.³

Limitations

The chief limitation of this review is the short publication period criterion (January 2015 – mid-2020). While this covers the new policy context in England that followed the Care Act 2014 coming into force, it excludes a substantial prior literature from the US focused on elder self-neglect. This weakness was ameliorated to some degree by our inclusion of international reviews on elder self-neglect, which took a longer view, such as those by Dahl et al. (2020) and Dong (2017).

It might also be (rightly) said that much of the evidence from England presented here derives from pre-Care Act practice. On the one hand, the work of Braye et al. that was published within our time-frame has been influential on the reception of the new legislation (and their research was cited in the Care Act 2014 statutory guidance). On the other, it might also present subsequent research initiatives, such as our own, with the opportunity to gauge the impact of the changing law and policy context on approaches to self-neglect.

Finally, it was beyond the scope of this review to consider health approaches to self-neglect, yet effective integrated or partnership working between health and social care is an important case of multi-agency working. In addition to the examples of integrated teams from Dublin (Smyth et al., 2018) and New York City (Diaz Narvaez et al., 2019), a 'health perspective', where the emphasis might be on self-care and self-management rather than self-neglect, appears to be an important avenue to explore further. Social prescribing may also be relevant here. If researchers are approaching the topic by way of safeguarding practice, they may counter the risk of silo scholarship by taking advantage of the constituent membership of Safeguarding Adults Boards (which include health partners).

³ Opening the "Too Difficult Box": Strengthening Adult Safeguarding Responses to Homelessness and Self-neglect – <https://www.kcl.ac.uk/research/homelessness-and-self-neglect>

Search strategy

Following extensive pilot searching to refine our strategy, database searches were conducted on 7-8 September 2020. Eighteen databases / online sources were searched, covering a range of relevant disciplines (see table below). Supplementary searches were conducted to identify further potential studies and publications. Approaches involved searching on general online search engines (e.g., Google), snowballing from publications and recommendations from colleagues.

Criteria for inclusion

- Published 1.1.2015 until date of search (7-8.9.2020)
- English language
- Peer-reviewed literature
- Focus on Adult Social Care (and international equivalents) responses to self-neglect
- Subject population: older people, using a guide age of 65 years and over (see note above)

Search terms for self-neglect:

self-neglect OR selfneglect OR "self neglect" OR hoard* OR squalor OR squalid OR "diogenes syndrome" OR unsanitary OR insanitary OR syllogomania

Search terms for older people:

older OR elder* OR ageing OR aging OR 'senior citizen*' OR geriatric* OR 'old age' [on some platforms, Ovid for example, we made use of the platform's own filters, including ones for older people]

On the UK-specific platforms we included variants of 'refusal' to capture refusal of services / care / assessment.

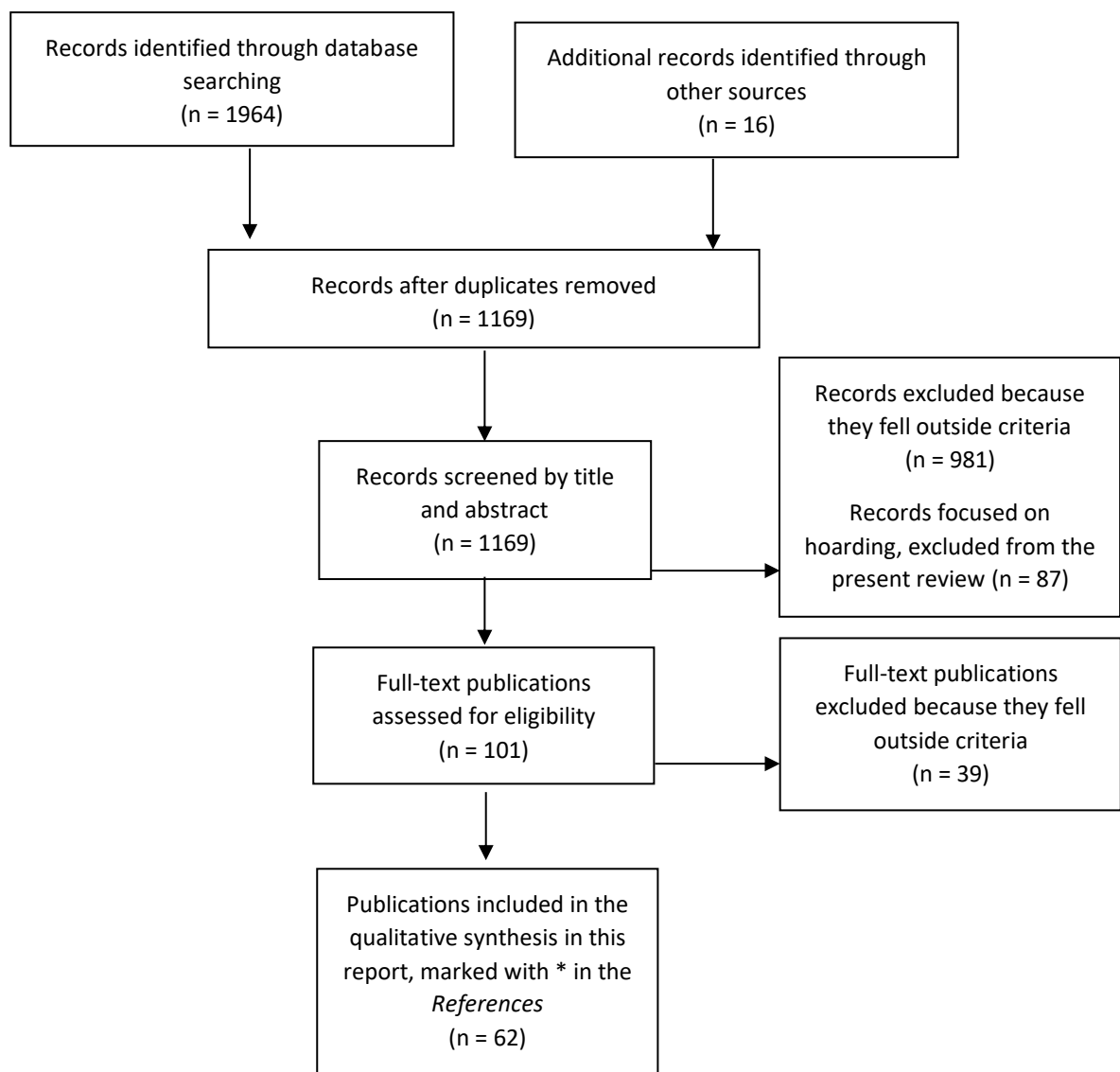
Database search results

Database/online source [platform]	Number of search results
Social Care Online	119
Social Science Database; Applied Social Sciences Index & Abstracts (ASSIA); Sociological Abstracts; Sociology Database; Social Services Abstracts [ProQuest Social Science Premium Collection]	265
Scopus [Elsevier]	208
Social Sciences Citation Index [Web of Science]	269
Social Policy and Practice [Ovid]	80
APA PsycInfo [Ovid]	125
Medline [Ovid]	140
Embase [Ovid]	201
HMIC [Ovid]	3
CINAHL [EBSCO Host]	97
NHS Evidence [NICE]	346
Cochrane Central Register of Controlled Trials	56
OpenGrey	0
AgeInfo	24
CareKnowledge	0
ETHOS [BL]	12
King's Fund database	1
Community Care	18
TOTAL (before de-duplication)	1964

Flow diagram of literature search

Database searches returned 1964 records, while other approaches identified 16 additional records. After removal of duplications, 1169 records were screened by title and abstract and 101 full-text papers were assessed based on the eligibility criteria. In total, 62 publications satisfied the inclusion criteria and were thus included in this review (this number includes the 17 'risk factor' studies reported in Appendix 2).

Of the 62 papers and reports included in the synthesis in this review, 22 derived from research in US populations, 18 publications were from England, and 14 publications were from countries apart from the US and England: Canada (1); China (2); the Netherlands (1); Ireland (4); Israel (2); South Africa (1); Spain (1); Thailand (1); Turkey (1). The remaining eight papers were international commentaries or reviews.



Appendix 2: Risk factors

This appendix gives an account of literature with an epidemiological focus that may inform practitioner and clinical approaches to the topic. Excluded from the main body of the report because not directly to do with Adult Social Care responses to self-neglect, findings from this literature may nevertheless bear on the detection and prevention of self-neglect. The prevention of needs for care and support is an imperative in England under s.2 Care Act 2014.

The literature review presented in this report (covering 2015-20) retrieved 17 studies involving an assessment of risk factors, none from England, 14 from the US, three from the rest of the world. Where associations were found by these studies, it was common for the authors to suggest that these should prompt clinicians and others to engage in routine screening as part of a programme of detection and prevention of self-neglect among older people. Our start date of 2015 (chosen because that is when most of the Care Act 2014 came into force in England) is arbitrary in respect of this kind of epidemiological research, but systematic reviews by Dyer and Reyes-Ortiz (2017) and Yu et al. (2020) provide a broader context (the latter overlapping with our date range).

In a systematic review of the English-language literature on self-neglect among those 60 years of age and above, Dyer and Reyes-Ortiz (2017) included 25 publications examining risk factors and associated disorders. The authors did not have a publication start date in their inclusion criteria; the earliest publication was Clark et al. (1975), the Diogenes Syndrome paper in *The Lancet*, and the most recent was from 2015. Cautioning that a lack of uniformity in definition and variation in methods of assessment had to be taken into account, the authors' summary list of risk factors was as follows:

- older age
- isolation
- lack of social support
- poverty
- personality disorders
- hoarding
- mental disorders: dementia, depression, substance abuse
- physical illness: stroke, diabetes, nutritional deficiency
- functional impairment

Yu et al.'s (2020) systematic review of the international literature of self-neglect and its risk factors among community-dwelling older adults searched databases from their inception to April 2020 and included 19 papers. Seventeen reported work predominantly conducted in the US, and two were from China. All included papers reported on observational studies. Mean ages ranged from 72.8 to 78.2 years; sample size ranged from 100 to 4,627. Depression and a lower level of physical function were the two most frequently reported risk factors across the papers. Other factors were: cognitive impairment; nutritional status; pain; lower social network and social engagement; lower neighbourhood cohesion; neighbourhood disorder; and, lower quality of life.

The following outlines the findings from our review (2015-20):

U.S. risk factor findings

Population Study of Chinese Elderly in Chicago (PINE study)

- Dong and Simon, 2016: (n=3,159; >60 years) Gradient relationship between poorer levels of **health status, physical function, cognitive function** and **depressive symptoms**, and greater risk for self-neglect and specific personal and environmental hazards. *Recommends: Healthcare professionals should consider screening for self-neglect among older patients who report cognitive impairment, physical disability and depressive symptoms.*
- Dong, 2016: (n=3,159; >60 years) **Older age** and **lower education levels** were significantly associated with elder self-neglect of all severities. Income levels were not associated with greater elder self-neglect in this Chinese population living in Chicago. *Recommends: Health*

care professionals should consider screening for self-neglect among older patients who are of older age or have lower educational attainment.

- Dong et al., 2017: (n=3,159; mean age: 72.8 years) After controlling for a wide range of potential confounding factors, the study found that a higher level of self-neglect was associated with increased risk of self-reported **suicidal ideation** in the past 2 weeks, 12 months, and over a lifetime. Phenotypes such as hoarding, poor personal hygiene, and unsanitary conditions were especially associated with increased risk of suicidal ideation. In addition, the association between self-neglect and suicidal ideation is particularly significant among the older adults with moderate to severe level of self-neglect. *Recommends: Screening instruments and effective intervention programs are needed to help improve the well-being of this ageing population.*
- Hei and Dong, 2017: (n=3,159; mean age: 72.8 years) Greater **neighbourhood cohesion** was associated with lower risk of overall self-neglect. *Recommends: Self-neglect prevention strategies should aim to strengthen cohesion as part of policy-makers' place-based strategies for health promotion.*
- Hei and Dong, 2018: (n=3,157; mean age: 72.8 years) Higher level of **neighbourhood disorder** significantly associated with greater risk of self-neglect. *Recommends: Lessening neighbourhood disorder may be an effective approach for self-neglect prevention among the Chinese American older population.*
- Wang et al., 2020b: (n=2,713; >60 years) Longitudinal study (2 waves, 2 years apart) developed a 19-item index with moderate to good predictive accuracy. Predictors: Individuals who **live with fewer people**, perceive poorer **family social support**, had **relatives died** recently, and experienced **elder abuse** were at higher risk of self-neglect.

Chicago Health and Aging Project (CHAP study)

- Wang et al., 2020a: (n=2,885; >65 years) Longitudinal study (2 waves, 3 years apart) developed a 10-item predictive vulnerability model designed for use without a home visit being necessary. Found, *inter alia*: **hypertension**, **shortness of breath**, no **aspirin** taken in the past three years were predictive of self-neglect. Although psychological distress and cognitive impairment are commonly concurrent conditions of self-neglect, results indicated that they are not independent predictors of self-neglect after adjusting for various factors.
- Dong and Simon, 2015: (n=1,228; >65 years) Reported and confirmed elder self-neglect is independently associated with increased rate of 30-day **hospital readmission**. Greater severity of self-neglect is associated with higher rates. *Recommends: Routine self-neglect screening for older people with history of multiple encounters with healthcare.*

Other U.S. risk factor studies

- Aamodt et al., 2015: Both squalor-dwelling older people (n=50; mean age: 74.8 years; Adult Protective Services (APS) clients) and non-squalor dwelling older people (n=180; mean age: 79 years; APS clients) performed poorly on **cognitive function** measures. The squalor-dwelling older people performed *better* on measures of memory and general cognition, even after adjusting for age and education, than the non-squalor-dwelling older people. 'These findings suggest that cognitive function alone is not sufficient to explain squalor-dwelling status' (p.71).
- Cornwell, 2016: Two-wave survey (2005-06 and 2010-11) of a nationally representative sample of 3,005 (W1) / 2,261 (W2) community-dwelling older adults aged 57-85 across the US. Those who had larger **social networks** and more supportive relationships with family and friends had less disordered households at baseline. Support from **family** members was negatively associated with subsequent household disorder. This study found evidence that older adults who reside in non-nuclear **households** had more disordered residences; those who resided with a partner and/or child had less disordered dwellings. The author concludes by urging greater attention to how the household context shapes—and is shaped by—the social interactions and processes that occur within it. This is a study of 'household disorder'

rather than self-neglect, drawing on the National Social Life, Health, and Aging Project (NSHAP).

- Schafer et al., 2020: (n=1,323; 57-85 years) Two-wave survey (2005-06 and 2010-11) of a nationally representative sample indicated that ‘a bundle of economic woes tied to economic decline are associated with concomitant declines in household order’ (p.390). The factors showing this association were **unemployment**, **household income**, and **foreclosure**. This is another study of ‘household disorder’ rather than self-neglect, drawing on the NSHAP. (An associated study directed at outcomes, also drawing on the NSHAP dataset, found that disorderly bodily self-presentation predicted mortality risk. Higher levels of household disorder predicted increased mortality risk: Schafer et al., 2018.)
- Hansen et al., 2016: (n=96; mean age: 76 years; APS-substantiated older people who self-neglect) Alcohol abuse, lower self-rated health, and higher self-reported pain are more likely among depressed older people who self-neglect compared to non-depressed older people who self-neglect. *Recommends: An interdisciplinary approach to care to manage multiple comorbidities and acute social service needs among depressed older people who self-neglect.*
- Lee et al., 2016: (n=37; >65 years; APS-substantiated older people who self-neglect) Large proportion of older people who self-neglect are **pre-frail** rather than frail. *Recommends: Intervention studies should aim to reduce move from prefrailty to frailty.*

Rest-of-world risk factor findings

- Charles et al., 2015, Canada: (n=224; >65 years; with cognitive impairment) Longitudinal study (over the course of one year). A patient self-report measure was a predictor of harm due to self-neglect or disorientation—specifically, being **depressed** and rating own **health as fair or poor** was a predictor. *Recommends: Use Geriatric Depression Scale and self-rated health scale in this group.*
- Day et al., 2016b, Ireland: (n=295 self-neglect case records; >65 years) Retrospective record review found: **Deprivation** and **poverty** were risk factors linked to higher numbers of self-neglect cases.
- Yu et al., 2019, China: (n=181; mean age: 75.3 years; living alone) Higher **depression** levels and lower monthly **income** significantly predict higher levels of self-neglect among this population.

Appendix 3: Self-neglect measures

Writing from within the English context, Braye et al. (2017a: 179) highlighted the lack of a “gold standard” array of assessment tools for use with self-neglect’, and Aspinwall-Roberts (2020: 275) suggested that standardised tools are ‘urgently needed’. Although our search was not directed at identifying measures of self-neglect, the evidence we found of them (none from England) is presented here. In her international commentary, Day (2020) drew attention to three measures:

Self-Neglect Severity Scale (US) (Dyer et al., 2006): ‘includes observational and self-report data and 3 domains of self-neglect as indicators: Personal hygiene (example: dirty hair, clothing, unkempt nails and skin), impaired function (example: decline in activities of daily living and cognition); and environmental neglect (example: unclean house or yard and inability to manage material goods accumulated over the years).’ (Day, 2020: 90)

Self-Neglect Assessment Measurement (SN-37) (Ireland) (Day and McCarthy, 2016): ‘includes 37 items and 5 factors: environment (12 items), social networks (7 items), emotional and behavioral liability (8 items), health avoidance (6 items) and self-determinism (4 items). Each item is completed based on three-point scale ranging from no evidence, yes, and don’t know.’ (Day, 2020: 90)

Geriatric Self-Neglect Scale (US) (Abrams et al., 2018): ‘has three subscales Subject, Observer, and the Overall Impression and six domains (prescription medicines, personal care, nutrition, environment/housing, financial stewardship and socialization).’ (Day, 2020: 90)

Another measure we saw frequently mentioned in the literature, and focusing on older people, was **Elder Self-Neglect Assessment (ESNA)** (US) (Iris et al., 2014), in which indicators of self-neglect align into two broad categories: behavioural characteristics and environmental factors.

İlhan et al. (2018) (Turkey) developed and tested a screening tool for self-neglect in community-dwelling older adults. The **Istanbul Medical School Elder Self-Neglect** questionnaire consists of 11 items related to personal hygiene, health habits, and social functioning. Designed for use in geriatric outpatient clinics, the authors claimed it would help in identifying patients who would benefit from a detailed social worker interview.

In his expert review, Dong (2017) suggests that, to his knowledge, Dyer et al. (2006), the scale mentioned above, which is also known as the Texas Self-Neglect Scale, and his own **Chicago Self-Neglect Scale** (Dong et al., 2012) are the only two measures that have been tested psychometrically. The latter evaluates self-neglect in the domains of hoarding, personal hygiene, house in need of repair, unsanitary conditions, and inadequate utilities.

Dong (2017) refers researchers to the chapter by Margot Schofield (2017), ‘Screening for Elder Abuse: Tools and Effectiveness’ (here, elder abuse includes elder self-neglect). Schofield covers both screening measures designed to screen at the community or population level and screening instruments designed for use in healthcare or institutional settings.

Appendix 4: Legislation relevant to self-neglect

The following list of laws applicable in England draws substantially on Braye et al. (2017c; 2020).

Public Health Act 1936. If premises are 'are in such a filthy or unwholesome condition as to be prejudicial to health' or are 'verminous' the local authority can require premises to be cleaned and disinfected (ss. 83-84). Local authority may carry out the work itself and charge the person (s.83). Section 85 provides for the '[c]leansing of verminous persons and their clothing.'

Prevention of Damage by Pests Act 1949. Contains local authority's duties and powers with respect to the presence of rats and mice.

Public Health Act 1961, s.36: Power to require vacation of premises during fumigation.

Mental Health Act 1983. Part II of the Act provides for compulsory admission to hospital and guardianship. Includes s.135: Warrant to search for and remove a person from premises where there is reasonable cause to suspect that they are suffering from mental disorder and certain other conditions are met. This section includes the situation where the person, 'being unable to care for himself, is living alone'—s.135(1)(b).

Public Health (Control of Disease) Act 1984. Powers to intervene in situations of disease or infection posing significant risk of harm.

Police and Criminal Evidence Act 1984, s.17(1)(e): Police may enter without warrant to save life or limb or prevent serious damage to property.

Building Act 1984. Contains local authority powers with respect to defective premises that are 'prejudicial to health or a nuisance' (s.76).

Housing Act 1985 (amended 1996) and **Housing Act 1988** provide grounds for eviction of a tenant.

Environmental Protection Act 1990. Gives the local authority power to require abatement of a statutory nuisance.

Human Rights Act 1998

Housing Act 2004. Duties and powers for local authorities to address hazards that pose risks of harm to health and safety.

Mental Capacity Act 2005

Animal Welfare Act 2006. Person has a duty to meet the welfare needs of their animals.

Equality Act 2010

Care Act 2014

Anti-Social Behaviour, Crime and Policing Act 2014. Local authority, housing provider or the police may obtain an Injunction to Prevent Nuisance and Annoyance (IPNA). Breach is a ground for eviction. Community Protection Notices (CPNs) are available to police and the local authority to address unreasonable conduct that is having a detrimental effect on the quality of life in the locality.

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