**“Good support isn’t just about**

**‘services’ – it’s about having a life.”**

Self-Neglect and Hoarding

Evidence Review Report

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# Introduction

This review looks at the complex and multi-faceted issues of self-neglect and hoarding. Although awareness has increased in the last decade, research and evidence is still lacking, and these phenomena are hard to define. They tend to be more prevalent in older people, although this may be due to the likelihood of older people having more reason to interact with social care and other statutory agencies. It is an aspect of social care that raises legal and ethical questions around if, when and how to intervene. This is about more than trying to establish if a person has the mental capacity and therefore the right to refuse support. It raises wider questions about people’s ability to safeguard or protect themselves from the impact of self- neglect and/or hoarding. It also requires scrutiny of the way adult social care is currently structured because supporting people who are self-neglecting and hoarding, to an extent that it is affecting their health and wellbeing, is a long-term process.

This evidence review provides an overview of the literature relating to definitions, prevalence, and the reasons behind self-neglect and hoarding. It will highlight the legal and policy context and what is known about how best to intervene.

**Note on terminology** - Self-neglect and hoarding are often grouped together in everyday conversations. In the literature, some see these as separate phenomena. Others view hoarding as a distinct manifestation of self-neglect. Additionally, some people object to the term self-neglect because it implies the person is responsible for their situation and they have been judged as lacking in some way. This evidence review acknowledges these divergent perspectives, but for the purposes of this review, will retain the term self-neglect and hoarding unless the point being made is specific to one or the other.

# Methodology

Four electronic databases: PubMed, Scopus, Google Scholar and Microsoft Edge were searched for literature reviews, legislation and policies on self-neglect and hoarding between April and June 2024 using the key words: hoarding, self-neglect,

literature reviews and social care. Searches included literature published between 2010 and 2024 and identified 28 publications of which duplicates (n=2), academic papers (n=23), and articles in professional publications (n=3). A general search was also carried out to identify legislation, policies and statutory guidance.

# Across Policy and Agency Concern

Self-neglect and hoarding are challenging areas for health and social care professionals as in its most serious form, the person’s health can be impacted to the extent they might be at risk of serious medical consequences or of dying without intervention. Families can be very distressed or may have distanced themselves some time ago. Neighbours and communities can be affected where the person’s home has become an environmental health or fire risk. This can lead to a much wider range of services being involved.

Morein-Zamir and Ahluwalia (2023) list a diverse set of front-line providers who can be the first to encounter someone with a hoarding disorder including housing officers, environmental health, fire, police, and ambulance services. These professionals are meeting an individual on a first responder basis without having a relationship with the individual or any training around this complex issue. Therefore, they will only be able to deal with the presenting issue and they will often refer onto to local authorities for further assessment and intervention. Figure 1 below shows the inter-agency involvement with people who self-neglect and/or hoard.

Figure 1: Multiple agencies that could be involved in supporting people with hoarding behaviour as suggested by Orr et al., (2017, p.11)



# Exploring self-neglect and hoarding

Research and literature in relation to self-neglect and hoarding has focused on the older population and Owen et al., (2022) argue that this is due to bio-psycho-social factors that may be exacerbated by advancing age. However, others argue that it is simply due to older people being more likely to be in contact with primary and social care services. Sanders (2022) concludes that because literature has focused on older people, it has rarely progressed beyond definition and identification. This has led to a notable lack of research on interventions or lived experience (Sanders, 2022).

Self-neglect and hoarding behaviours are often grouped together, or hoarding is seen as a sub-category of self-neglect. However, the Social Care Institute for Excellence (SCIE) states that one does not necessarily cause the other (SCIE, 2018).

## Self-neglect

Self-neglect, sometimes also referred to as self-harm, is described as a complex, multi-dimensional concept that was first identified in the 1950s with behaviours that are difficult to define, measure, and address. Self-neglect can manifest in different ways. Barnett (2016) states that it may be due to the person being physically unwell and unable to cope with their own care needs. It may also occur as a result of dementia, brain damage, depression, a mental distress, or substance misuse, including prescribed medication. Another explanation is that people who neglect their health and wellbeing are affected by past trauma such as bereavement, abuse and neglect, violence and experience of war (Barnett, 2023). Feelings of loss of power or control experienced at the time can emerge later. Other impacts of past trauma include hyper-vigilance to perceived threat or mentally closing down emotional responses. The person may isolate themselves as a means of self-preservation and there might be a deep mistrust of other people, especially professionals. The danger here is that professionals will presume that people are choosing to live that way. Outbursts of anger might be viewed as evidence of an aggressive nature. Whatever the cause the person themselves may not realise the level of self-neglect they are suffering, or they may recognise it but are unable to address it. This has led Barnett (2023) to challenge the use of the term ‘self-neglect’ and suggest using neglect on its own.

## Hoarding

Hoarding behaviour is referred to both as ‘hoarding disorder’ and ‘hoarding behaviour’, being more often referred to as a ‘disorder’ in legislation and statutory guidance.

There is no particular gender, age, ethnicity, socio-economic status, education or occupational attainment characteristic of those who hoard. It can cause significant distress or impair work or having a social life (Sanders, 2022). Hoarding behaviour

can begin following a significant event, such as a bereavement, when objects can be associated with emotional attachments. People who hoard can become socially isolated, alienating family and friends as they may be too embarrassed to have visitors. They also often suffer from anxiety and although typically able to make rational decisions not related to hoarding, they may not see anything wrong with their hoarding behaviour and the effect it has on others (Barnett, 2016). Hoarding behaviour is also associated with high healthcare and housing costs, poor mental health and housing insecurity. These factors contribute to the complexity of engaging with people who hoard and working with them to achieve change (Gardelli, 2022). In its more serious form, it can be a significant challenge for social landlords and for neighbours, whether the person owns their own property or not, as the fabric of the building can be affected or there might be an increased risk of fire.

# Definitions

## Hoarding

Hoarding was recognised as a discrete mental health disorder when it was revised from being a diagnostic criteria for Obsessive Compulsive Disorder (OCD) to being classified as a stand-alone condition, first in the Diagnostic and Statistical Manual of Mental Disorders (5th ed), (DSM–5) (American Psychiatric Association, 2013) and later in the 11th revision of the ‘International Classification of Diseases’ (11th ed.), (ICD-11), (World Health Organisation, 2019). DSM-5 states that to be categorised as hoarding behaviour it ‘…must cause significant distress or impairments in functioning and cannot be attributed to another medical or psychiatric disorder’ (American Psychiatric Association, 2013).

Although there is no definitive definition of hoarding, it described in the DSM-5 as a persistent difficulty in discarding possessions resulting in cluttered living spaces which compromises their intended and safe use. (American Psychiatric Association, 2013). In the ICD-11 (WHO, 2019) describes the characteristics of hoarding behaviour (disorder) as being:

“… characterised by accumulation of possessions due to excessive acquisition of, or difficulty discarding possessions, regardless of their actual value. Excessive acquisition is characterized by repetitive urges or behaviours related to amassing or buying items. Difficulty discarding possessions is characterized by a perceived need to save items and the distress associated with discarding them. Accumulation of possessions results in living spaces becoming cluttered to the point that their use or safety is compromised. The symptoms result in significant distress or significant impairment in personal, family, social, educational, occupational or other important areas of functioning,” (WHO,2019).

## Self-neglect

There is no definitive definition of self-neglect either, Gibbons (2006) defined it as “the inability (intentionally or unintentionally) to maintain a socially and culturally acceptable standard of self-care with the potential for serious consequences for the health and wellbeing of those who self-neglect and perhaps too to their community,” (cited in Sanders, 2022 p.2). SCIE describe rather than define it as “lack of self-care to an extent that it threatens personal health and safety; neglecting to care for one’s personal hygiene, health or surroundings; inability to avoid harm as a result of self-neglect; failure to seek help or access services to meet health and social care needs; inability to manage one’s personal affairs.” The Social Care Institute for Excellence (SCIE) lists possible causes:

* Brain injury, dementia or other brain disorder
* Obsessive compulsive disorder or hoarding disorder
* Physical illness which has an effect on abilities, energy levels, attention span, organisational skills
* Reduced motivation as an effect of medication
* Addictions
* Traumatic life change (SCIE, 2024).

Equally, the review of evidence by Sanders (2022) for the Institute of Research in Social Services in Scotland noted: “At its most basic, self-neglect is an inability to care for your basic needs. It can include cumulative, diverse behaviours that threaten self-care, combined with resistance to receiving care from others. It can vary in presentation and severity, and covers a progressive decline in personal, social, physical, mental, and/or environmental domains” (Sanders, 2022, P3.). It is therefore important to note that there is a subjective element to professionals’ perspective on what is and is not self-neglect, and that the person being described may not use it to describe their own situation (Braye and Preston-Shoot, 2020).

The recognition that social work, but also other welfare agencies, struggle to recognise and to address self-neglect has led to local authorities across the UK developing guidance to support practitioners. For example, Tayside Practitioner’s Guidance: Self-Neglect and Hoarding Protocol and Toolkit provides an overview of the approach to self-neglect and hoarding to aid assessment and intervention (Angus, Dundee City and Perth and Kinross Councils 2020). The toolkit is designed to support Health and Social Care Partnerships, Police Scotland, NHS, Housing Services, Substance Use Services and other relevant social care providers including third sector organisations. The guidance states that extreme self-neglect can be known as Diogenes syndrome, a disorder characterised by extreme self-neglect, domestic squalor, social withdrawal, apathy, compulsive hoarding of garbage, and lack of shame. Sufferers may also display symptoms of catatonia meaning they might not speak and be immobile.

# Prevalence

As there is no clarity in defining self-neglect there is also no clarity on prevalence. Equally though, there is no data on hoarding. Data collection in relation to adult safeguarding in both England and Scotland has been noted as unreliable due to the varied ways agencies and their practitioners might record the main presenting concern (NHS Digital, 2022 and the Scottish Government 2023). In England, people who self-neglect is recorded as approximately 9% of all adult safeguarding enquiries being undertaken. In Scotland, there is no separate category of self-neglect and it is subsumed under neglect which could mean omission by others. Together they make up 17% of the number of investigations undertaken. Neither country specifies hoarding as a separate category of harm, and practitioners would either these behaviours under neglect or record as ‘other’. However, there is a sense that the number of people who neglect their wellbeing and health is rising; and following Covid-19 the increase in numbers is expected to continue to rise (Pickens, 2021 in Owen, 2022).

With no typical presentation of self-neglect and with cases varying in terms of age and household composition, data from general practitioner caseloads in Scotland reported rates in Scotland from 166-211 per 100,000 population (Day, 2016 in Sanders, 2021).

Various studies have estimated the prevalence of hoarding. It is estimated that between 1.5 and 6 of the population may meet the definition of hoarding disorder (British Psychological Society [BPS], 2024). The BPS also estimates that only 5% who meet the definition of hoarding disorder will seek help. This is possibly due to not viewing themselves as hoarders as ‘clutter-blindness’ can mean they become immune to the clutter in the house and stop noticing it or they may not seek help due to feelings of shame. Hoarding can also lead to death with suggestions that 25% of accidental domestic fire fatalities result from hoarding (Dumfries and Galloway Self-neglect and Hoarding Protocol). The literature suggests that mainly older people hoard, and it is a problem that develops over a number of years (BPS 2024). A low-level issue with hoarding can be exacerbated from a bereavement or other traumatic incident. There is also a likelihood of hoarding in younger adults, given that trauma linked to trauma, often happens in childhood. It is also thought that the number of younger people engaging in hoarding behaviour is growing with an increase in awareness of the issue (BPS 2024).

# Legislation and Statutory Guidance

Social care is a devolved responsibility to each of the four UK nations. People who self-neglect and hoard may be eligible for assessment and support under general social care legislation due to physical, cognitive or learning disabilities, poor mental health or poor physical health. Given that people who hoard or self-neglect do not often seek help themselves, it is likely that more severe situations will come to the attention of social work agencies under adult safeguarding legislation and policy:

* The Care Act 2014 in England
* Adult Support and Protection (Scotland) Act 2007
* Social Services and Wellbeing (Wales) Act 2014
* Adult Safeguarding: Prevention and Protection in Partnership Policy (2015) in N. Ireland

Each nation’s code of practice or policy has been linked in the reference list for those who wish to explore this aspect further.

In brief, there is variation in the definitions of an adult at risk of harm or an adult that is unable to protect themselves across the four nations. The focus in this section though, is on the extent to which self-neglect and hoarding have featured in the legislation or policy. Law reform was led by the respective Law Commissions at various points from the late 1990s onwards in England, Scotland and Wales and then picked up as a priority for new legislation by their respective government or assembly. For example, an English series of scoping studies in adult social care by its Law Commission in 2011, identified an historic lack of understanding around self-neglect that had resulted in inconsistent approaches to care and support. Whilst the ensuing statute, The Care Act 2014, did not refer to self-neglect, it did formally recognise self-neglect through allied Statutory Guidance requiring responses from Local Authorities (LAs) and their partners (DHSC, 2024). In comparison, the Adult Support and Protection (Scotland) Act 2007 named self-harm in the statute and then subsequent allied Codes of Practice have defined this more in terms of self-neglect (Scottish Government 2008, 2014 and 2022). Each subsequent version demonstrates an improved understanding of the causes of self-neglect and of how hoarding might mean a person meets the definition of an adult at risk of harm. Wales, like England, did not note self-neglect or self-harm in the statutes but they are contained in the guidance. Northern Ireland does not address self-neglect in its policy (NIDHSC, 2015). This omission was noted in a critique of the Northern Ireland policy (Montgomery & McKee, 2017). However, this is not to say that adult safeguarding staff in NI will not be engaging with people for reasons of self-neglect and hoarding.

In self-neglect and hoarding situations there may be questions about a person’s mental health or their mental capacity which require practitioners to then consider the mental health and mental capacity legislation in their nation. This underlines the need for practitioners to have legal literacy (Braye, Orr and Preston-Shoot, 2024).

Research and evaluation to date has highlighted that there can be inconsistencies in agencies applying law and policy in practice. Within the English legislation/context, Owen et al., (2022) explored adult safeguarding managers’ understanding of self-neglect. They point out that local teams work differently and constraints around time and resources often mean that whoever has won the person’s trust will act as a bridge for other interventions. Also, the question of whether people are choosing to adopt a particular lifestyle rather than requiring support can present legal and ethical problems for practitioners.

In Scotland, variations in practice in safeguarding in general have also been noted (Care Inspectorate & Her Majesty’s Inspectorate of Constabulary [CIMIC], 2018). For this reason, the Scottish Code of Practice stresses that ability to safeguard is not the same as mental capacity. It goes on to say there is a need to assess whether a person is unable or unwilling to protect or care for themselves; understands the consequences of their actions; and also, whether they are unable or unwilling to take the steps required to protect or care for themselves (Scottish Government, 2022). When a person’s mental capacity is uncertain, it is important for this to be assessed in order to inform professional decision-making and responses (Owen et al., 2022).

## Scotland

The IMPACT project this evidence review is written for is based in Scotland and this section provides a brief overview of the Adult Support and Protection (Scotland) Act 2007 (the Act). It is also possible that people who self-neglect and hoard might be considered under the Adults with Incapacity (Scotland) Act 2000 (ASPSA) and the Mental Health (Care and Treatment) (Scotland) Act 2003.

Part 1 of the ASPSA introduced new measures to identify and protect adults at risk from harm. These include:

* a duty on Councils to make inquiries (making use of investigative powers as need be) to establish whether or not action is required to stop or prevent harm occurring,
* a requirement for specified public bodies to co-operate with local councils and each other in investigating suspected or actual harm,
* the introduction of a range of protection orders, namely assessment orders, removal orders and banning orders, and
* a legislative framework for the establishment of local multiagency Adult Protection Committees (APCs) across Scotland.

 As a result of the ASPSA, Scotland’s adult safeguarding legislation is seen as being more interventionist. The two protection orders that might be used in self-neglect and hoarding are firstly, the assessment order that can remove a person to a place of assessment and secondly, a removal order to place the person in a place of safety for up to seven days but cannot keep them there. The Sheriff Court approves all protection orders and can grant a police warrant for entry to ensure access to the person is gained.

The principles of the Act (Sections 1 & 2) require that any intervention under the Act must provide benefit to the adult which could not reasonably be provided without intervention and must be the least restrictive option available which benefits the adult.

The definition of an adult at risk (aged 16 and above) is as follows:

(a) unable to safeguard their own well-being, property, rights or other interests,

(b) are at risk of harm, and

(c) because they are affected by disability, mental disorder, illness or physical or mental infirmity, are more vulnerable to being harmed than adults who are not so affected (S3 (1)).

Adult Protection Committees (APCs) were established by local authorities to monitor and review the work being undertaken in their local area to safeguard adults; and are made up of senior staff from the agencies involved in protecting adults including staff from housing, NHS and the police and fire service. APCs are chaired by independent

convenors whose role is to have an overview in each council area and make recommendations to ensure adult protection activity is effective. APCs are required to supply biennial reports to the Scottish Government and to involve people with experience in the work of the APC, however, there have been various degrees of success (CIMIC, 2018). Lastly, the APC can commission learning reviews to explore where things may have gone wrong in the hope of improving response to adults at risk of harm in the future. A significant number of these involved self-neglect situations (Care Inspectorate, 2023).

Aberdeen City Health and Social Care Partnership [ACHSCP], in which this project is taking place, like many others, produces specific guidance and recognises the need to improve responses and develop specific guidance to support practice. Their ‘Multi-Agency Guidance for Managing Self-neglect, Hoarding and Non-Engagement’ [ACHSCP 2024] provides a framework to compliment any single agency’s protocol or guidance with assessment and intervention for self-neglect and hoarding. For example, summarising key issues to consider as in Figure 2.

Figure 2: Multi-agency Guidance for Managing Self-neglect, Hoarding and Non-Engagement

Source: Aberdeen City and Health Care Partnership

# Theoretical Perspectives of Self-neglect and Hoarding

There are several models of self-neglect and/or hoarding (Owen et al., 2022; Martineau et al., 2021; Roane et al., 2017). For example:

* A psycho-medical model views self-neglect as a product of underlying mental health issues or a pathological personality. Hoarding is often, although not always, associated with other disorders such as OCD (BPS, 2024).
* A social constructionist view argues that self-neglect should be understood in relation to cultural and historic norms of hygiene and cleanliness and views it as an objective phenomenon created by social, cultural and professional judgement. In the context of hoarding, tolerance of eccentricity impacts on how self-neglect and hoarding are viewed in public discourse.
* Bio-psycho-social model views the interaction of internal and external factors and their association with self-neglect.
* Cognitive behavioural approaches are more widely accepted in practice. Since these models propose that self-neglect and hoarding arise from patterns of thoughts, beliefs and behaviours, intervening in beliefs and thoughts with therapies such as Cognitive Behavioural Therapy (CBT) could offer an effective treatment (Owen et al., 2022).
* Given that trauma can trigger self-neglect or hoarding, trauma informed practice by all those who are in contact with the person is important (NHS Education for Scotland, no date)

Maier’s (2004) literature review looking at phenomenology and classification of hoarding concludes that this is a complex behavioural phenomenon associated with different mental disorders. Maier argues that the psychopathological structure of hoarding has elements of OCD, impulse control disorders and ritualistic behaviours, with self-neglect as a possible consequence. Therefore, the term ‘hoarding’ is of limited value in guiding therapeutic interventions and recommends every person be evaluated in relation to the concepts of elements of OCD, impulse control and ritualistic disorders (Maier, 2004). It is estimated that 20-30% of OCD sufferers are hoarders (Chartered Institute of Environmental Health).

# Support and Interventions

The literature on self-neglect and hoarding has common advice about how to assess and intervene.

## Assessment tools

A key difference is that, in relation to hoarding there are a number of standardised assessment tools that have been developed (BPS, 2024). For example, a common tool used across the UK is the Clutter Image Rating Scale (Frost et al., 2008). It can be used to assess the clutter in each room. There is no such general rating scale of self-neglect though medical assessments are key to establishing the degree of impact of self-neglect on the person. However, the same advice is offered in terms of the challenges of speaking to a person who may be fearful and reluctant to engage with professionals and let them into their homes: to try to build a relationship with the person which is covered in the next section.

## Getting the basics right

Both areas of literature state the need to demonstrate respect and build a relationship. In relation to self-neglect, Braye, Orr and Preston-Shoot (2024, p1), based on many years of research, state that “at the heart of self-neglect practice is a complex balance of knowing, being and doing:

* knowing, in the sense of understanding the person, their history and the

significance of their self-neglect, along with all the knowledge resources that

underpin professional practice.

* being, in the sense of showing personal and professional qualities of respect,

empathy, honesty, reliability, care, being present, staying alongside and

keeping company.

* doing, in the sense of balancing hands-on and hands-off approaches, seeking

the tiny opportunity for agreement, doing things that will make a small

difference while negotiating for the bigger things, and deciding with others

when the risks are so great that some intervention must take place”.

Barnett (2021) based upon a thematic safeguarding adult review, similarly, argued that the standard model of care management (short term intervention assessment, care planning) is ineffective. She stresses that since self-neglect and hoarding is often the result of survival strategies as a reaction to trauma, that nothing will work until a key person builds a relationship of trust, listening to them and learning their life story. This can be a protracted process, but when trust has been built, that person can act as a link to other healthcare professionals and agencies that are able to offer help and support. A key aspect of trauma informed practice (NHS Education for Scotland [NES] 2024) and also a finding from general adult safeguarding research, is the importance of giving choice and control to the person in situations where they feel powerless (Mackay, 2017).

## The Voices of People Who Have Accessed Services

These are largely absent in the self-neglect literature and are largely absent from the research in general. Braye, Orr and Preston Shoot (2024, p.6/7) is the one exception to this: People who use services emphasised the following as being important components of helping -

The practitioner’s ability to:

· show humanity

· be reliable

· show empathy

 · demonstrate patience

· be honest

· work at the individual’s own pace.

Some contrasted this approach with other, less helpful input that they had received, described with words such as ‘nagging’, ‘bossing’, ‘grating’, ‘criticising’ and ‘pushy’. When practitioner approaches were experienced as overly directive in this way, they were deeply unwelcome; and not only did they make a positive working relationship less likely, they also sometimes provoked resistance to otherwise constructive suggestions. Interviewees considered that it was entirely possible for practitioners to

get them to make significant progress by being less overtly directive. They preferred to be ‘encouraged’ to do things rather than ‘pushed’, and valued it when, for example, workers knew “when to back off a little bit” or when “they don’t force nothing on you”. Practical, hands-on help was valued, as were those moments when workers ‘go that extra mile’. This underlines the value of lived experience in guiding development in social care of policy and also practice guidance.

## A Multiagency Approach

Addressing self-neglect and/or hoarding is rarely a single agency endeavour. Whilst social care and community health-based staff are critical to the success of any intervention; police, the fire service, housing and specialist mental health and substance misuse teams can also be involved. It is therefore crucial that agencies learn to work effectively with each other (Martineau et al., 2021) because whilst there may be specific multi-agency protocols to respond at a local level, these are not consistently adopted nationwide. Challenges with multi-agency involvement include silo working, the roles of other professionals not being understood, a lack of a shared language relating to self-neglect and differing professional values and perspectives about the right thing to do.

In qualitative research carried out with landlords, Gardelli, (2022) also identified barriers to collaboration with different agencies around information sharing, conflicting perceptions around professional boundaries and a lack of understanding of other agencies roles in relation to health and social care and housing. Private landlords found it was not always clear how responsibilities were shared between the different sectors, and it was challenging to get help and support from the adult protection team unless their tenant had other mental health issues or support needs apart from hoarding. This was unsurprising given the pressures on time and resources (Gardelli, 2022).

## Intervening

 It was found that if more radical interventions were necessary such as deep cleans or removal of the person to another place of residence, they worked better where relationships of trust had been established. Without agreement by the person, the impact of an enforced action could further traumatise, make them even less trusting of welfare services and it does not address the underlying reasons for the hoarding or self-neglect in the first place (Barnett, 2016). Besides specialised counselling, mental health support and treatment of physical conditions, there are range of practical actions that can support the person to improve their wellbeing. These include improving house security, budgeting and shopping, accessing benefits and grants, care and repair housing services for small aspects of house maintenance, and reducing social isolation.

This breadth of activities reflect Owen’s (2022) assertion that ultimately, professionals develop practice wisdom in how best to work with self-neglect and hoarding. As Braye, Orr and Preston-Shoot (2024, p.5) state ‘there is no ‘one size fits all’ solution to self-neglect; it was recognised that each person’s circumstances resulted from their individual history, outlook and the specific mix of issues they were facing’.

A key message from practitioners is that working with people who self-neglect is professionally challenging but also emotionally demanding and therefore they need trauma informed supervision and agency support; in particular, the motivation and means to pull key people together to make decisions and activate plans where there is serious risk of harm or death (Barnett, 2021). Figure 3 drawn from Barnett (2021) is presented below as it summarises the key considerations and actions in initially offering help and support. It should be noted that the S.47 referred pertains to The Care Act 2014 for England only.

Figure 3: Key considerations in interventions offering support



Source: Barnett (2021) ‘Thematic Safeguarding Adult Review’

## Counting the Cost and Effectiveness

In relation to hoarding, it is estimated that the average cost of intervening in a hoarding case can be up to £60,000 (Dumfries and Galloway Self-neglect and Hoarding Protocol). This takes account of the range of professionals involved, house repairs, ‘deep cleaned’ and specialist agency involvement. Lee et al., (2022) were critical of the fact that there was little research on the effectiveness of intervention, recidivism rates and harm caused by intervention in the management of squalor (a term used in Australia) in older people.

It has been claimed that multi-disciplinary person-centred interventions are successful in supporting and improving the wellbeing of older persons who self-neglect and/or hoard. However, Thompson et al., (2017) in Owen, 2022, disputes this, claiming that while specialist treatment can bring about a reduction in the impact on the person it is usually modest (14-40% reduction), many participants remain in the range to be classified as hoarders. This though, should not necessarily be viewed as the intervention having failings as such reductions may be enough for someone’s home to become a safe and healthier place to live.

Family and neighbours can be critical of professionals, but there is a limit to the actions they can legally take where, for example, the person is deemed to have mental capacity, (although mental capacity is not a justification for inaction). Even where statutory agencies do take action sometimes the person can suffer serious harm or die due to their own actions or inaction.

# Conclusion

Increased awareness of self-neglect and hoarding behaviour is evidenced by its incorporation in statutory guidance and policy. However, there has been limited research around the effectiveness of interventions, either based on government legislation and policy or among community organisations. Research is also limited that incorporates the voices of those with lived experience of self-neglect and/or hoarding.

It is a complex and challenging aspect of social care and due to the uniqueness of each person who self-neglects and/or hoards; there is no one size fits all approach. Instead, this is time intensive and long-term work, the success of which rests on the practitioner’s ability to build trust relationships and to develop an understanding of the person’s life history and current circumstances. Additionally, there is need for agency support for practitioners who undertake this work and for local areas to develop effective multi-disciplinary and inter-agency networks to address the multi-faceted nature of self-neglect and hoarding.

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