Policy Statement for Self-Neglect & Hoarding

Version	3
Ratified By	WSAB
Date Ratified	8/12/2016
Author(s)	WSAB Policy & Procedures Sub Group
Date Issue	8/12/2016
Review Date	8/12/2018

Contents

Purpose:

This policy statement outlines Warrington Safeguarding Adults Board's expectations for practice in relation to individuals who self-neglect, which may include elements of hoarding behaviour. Individual agencies are encouraged to develop their own internal procedures but they should be concordant with this policy statement. At its core is a commitment to multi-agency partnership working as an effective approach to achieve positive outcomes, underlined by the principles of empowerment.

This guidance is also written with the understanding that specific training and development in understanding self-neglect, hoarding behaviours and the Mental Capacity Act is made available to develop the workforce ability to respond to this complex issue.

Introduction

Responding to self-neglect can be one of the most complex areas of practice for today's professionals, partly because self-neglect and hoarding often present within the context of personal choice. This creates a tension between a fundamental aim of safeguarding, that of reducing risk and implementing Making Safeguarding Personal (MSP). Individuals experiencing self-neglect can often put themselves and others at risk through their actions e.g. by creating a fire hazard

The Care Act Statutory Guidance acknowledges that self-neglect is not necessarily a safeguarding issue stating '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' (Chapter 14.17).

Whilst there are circumstances when self-neglect does become a safeguarding concern, it is more often appropriately dealt with as an intervention under the parts of the Care Act dealing with assessment, planning, information, advice, and prevention. Responses to self-neglect should be individually tailored to the person and the situation, involving them as much as possible and taking into account their capacity, rights, needs and desired outcomes. It is important that the professionals involved strive throughout to balance protection and choice. Failure to effectively intervene impacts on the individual, the community and the collective wellbeing of the multi-agency partnerships. This can include both failing to act when the situation requires it, or unlawful actions breaching a person's rights.

The Human Rights Act outlines the state's responsibilities to both safeguard and respect its citizen's rights to life, liberty, property, due process and privacy – all of which are particularly relevant in self-neglect situations, placing a responsibility on the state to only intervene where necessary. With the implementation of Safeguarding Adult Reviews (SARs) the level of scrutiny on professional practice has been clarified making it crucial that basic practice expectations are clear to all.

Definitions

Self-neglect means potentially putting oneself at risk of serious harm by not taking adequate care of one's own health and environment, and not taking adequate steps to meet one's own care needs.

The Care Act Statutory Guidance recognises self-neglect as a form of abuse that covers a wide range of behaviours such as neglecting one's personal hygiene, health and surroundings including harmful hoarding behaviour. Other literature on self-neglect suggests that it can include: persistent inattention to personal hygiene or environment; repeated refusal of services which can reasonably be expected to improve quality of life; self-endangerment as a result of unsafe behaviours.

Hoarding behaviour is the excessive collection and retention of any material to the point that it impedes day to day functioning (Frost & Gross, 1993). Pathological or compulsive hoarding is a specific type of behaviour characterised by: acquiring and failing to throw out a large number of items that would appear to hold little or no value; severe 'cluttering' of the adults home so that it is no longer able to function as a viable living space; significant distress or impairment of work or social life (Kelly 2010).

Hoarding disorder is distinct from the act of collecting, and is also different from people whose property is generally cluttered or messy. It is not simply a lifestyle choice. The main difference between a hoarder and a collector is that hoarders have strong emotional attachments to their objects which are well in excess of their real value.

Understanding Self-Neglect & Hoarding

According to the Social Care Institute for Excellence there is no one clear view of self-neglect as an issue. It can be described across a spectrum from psycho-medical condition to a socio-cultural issue of values. In reality the models used to help define it draw on mental, physical, social and environmental factors to help professionals understand how a person comes to reside in unsafe living conditions with an apparent lack of insight into the risks (SCIE report 46).

Research suggests that self-neglect in those with strong senses of self-sufficiency and a connectedness to place and possessions can of be a result of traumatic history or a life changing event. Age related changes may also be a factor, resulting in functional decline; cognitive impairment; frailty or psychiatric illness, thereby increasing a vulnerability to self-neglect as well as an increase the potential for developing a number of underlying health conditions. Some adults who decline to engage with services may do so because of diagnosed or undiagnosed mental health needs, unassessed cognitive impairments, or mistrust of public agencies. However, professionals should not develop rigid concepts of those likely to self-neglect as there may be overlap in causal factors.

Whilst there is no one single effective intervention model, learning suggests professionals need to establish relationships over time and utilise risk assessment tools sensitively.

Focus and activity around daily living tasks may also be more beneficial to achieve longer term change. Guidance suggests that the individual needs to be able to demonstrate not only that they understand their situation, but that they are also actioning the decisions they make in relation to their circumstances.

Self-neglect is associated with a range of factors;

- physical health issues: impaired physical functioning, pain, nutritional deficiency;
- mental health issues: depression, frontal lobe dysfunction, impaired cognitive functioning;
- use of substances: high alcohol consumption, use of other drugs;
- psycho-social factors: diminished social networks, limited economic resources, personality traits, traumatic histories and life events, high perceived self-efficacy.

Indicators of self-neglect to be alert for:

- Neglecting health and personal hygiene leading to pressure ulcers or skin damage
- Neglecting home environment, leading to hazards in the home or infestations
- Poor diet and nutrition leading to significant weight loss or other health issues
- Lack of engagement with services/ agencies
- Hoarding items – excessive attachment to possessions

Things to be alert for in your practice:

- The perception that this is simply a 'lifestyle choice'.
- Over reliance on previous assessments or decisions about eligibility, engagement, risk or capacity
- Lack of multi-agency working and information sharing
- Lack of engagement from the individual or family
- Challenges by the individual/ family to activity that minimises risk
- Making unsupported assumptions about family/ carer or other support available
- De-sensitisation to/from well-known cases, resulting in minimisation of need / risk
- Unwise decisions & withdrawal whilst at risk of significant / serious harm
- Individuals with chaotic lifestyles and multiple or competing needs

For further guidance & information see:

SCIE Report 46: Self-neglect and adult safeguarding: findings from research. 2011 - Indicates that intervening successfully depends on practitioners taking time to gain the adults trust and build a relationship, and going at their own pace.

SCIE Tenants who self-neglect; Guidance for frontline housing staff and contractors

SCIE Self-neglect policy and practice: research messages for practitioners. 2015.

Understanding Hoarding Behaviour

It is recognised that hoarding can be a distinct illness, or part of another health problem, for example, part of the symptoms of dementia. However, professionals should not assume that hoarding is always a sign of a mental health need, as there is no distinct type of individual that may hoard and in each case the materials collected will vary. The nature of material collected can be categorised into 3 types; inanimate objects, animals or data (including physical equipment and electronic data).

Hoarding Characteristics:

- Fear and anxiety
- Excessive attachment to possessions
- Indecisiveness in relation to discarding items, including rubbish
- Socially isolated – alienation of other and refusal to engage with services
- Have a large number of pets
- Mentally competent – in areas other than their hoarding
- Extreme clutter preventing rooms from being used for intended purposes
- Poor insight into their own behaviour

Individuals who display hoarding behaviour may well appear well-presented and when outside of their home give no indication of the issues they have. Others may neglect both aspects of their life.

Professional responses need to be sensitive as the individual will have attachment to the items collected and removing them will have an emotional impact and could potentially limit or damage longer term change.

For further guidance & information see:

Working with people who Self-Neglect: Practice Tool – includes practice tips, a case study, detailed assessment and legal resources

NHS Choices – Overview of Hoarding Disorder - Includes distinction between hoarding & collecting, indicators and potential treatments.

A Psychological Perspective on Hoarding – British Psychological Society PDF that provides guidance to those working with individuals that hoard.

Hoarding and how to approach it – guidance for Environmental Health Officers and others – This is a professional practice note that provides an overview of the issue, the statutory powers to address it, and case studies to highlight possible responses.

Principles of Effective Responses

SCIE[1] research into self-neglect practice is clear that there are key aspects to an effective approach in practice, based on views of professionals and service users and identifies:

[1] http://www.scie.org.uk/publications/reports/69-self-neglect-policy-practice-building-an-evidence-base-for-adult-social-care/files/report69.pdf

- the importance of establishing good rapport and non-judgemental, relationships
- 'finding' the person
- legal literacy
- creative interventions
- practical support
- patient and persistent negotiation
- respectful curiosity and challenge
- effective multi-agency working

The WSAB principles have been adapted from this guidance and research to create a framework of expectations for agencies to utilise in their approach to self-neglect and hoarding. Concrete rules cannot be provided as each case must be responded to individually, however, the principles outlined below set out some basic requirements for a robust approach to each case.

1. All professionals must work in partnership to achieve the best outcome for the adult with a focus on person centred engagement and risk management.

2. Agencies need to ensure that flexibility is applied in cases that require time and patience. While this may present challenges, it is essential that practice in these cases follows research guidance and allows for rapport and relationships to be established

3. Where there are concerns about risk to the adult or others and there are significant challenges to identifying a pathway to support reduction of the risks; professionals need to create an appropriate forum for case discussion to take place. They should utilise internal opportunities for discussion including supervision and agency escalation procedures in order that they can be supported, interventions reviewed and developed and risks escalated.

4. All agencies are responsible for triggering multi agency meetings to share concerns and to facilitate a case discussion where the most suitable lead agency can be identified based on relationships with the individual.

5. Where cases meet safeguarding thresholds then the multi-agency safeguarding procedures will be followed. Considerations will include the level of assessed risk and the adult's ability to protect themselves by controlling their own behaviour. Safeguarding Strategy Managers will lead on coordinating a safeguarding response.

These principles are underpinned by the following expectations of staff working with adults who self-neglect and /or hoard:

- Agencies must not have rigid Did Not Attend (DNA) policies that do not take into account reasons for DNA such as literacy, capacity, mental health issues, coercion & control features, requirements for adjustments to attend.

- Professionals should retain a level of professional curiosity in relation to service users to ascertain when repeat service users may have self-neglect or hoarding backgrounds facilitating continued presentation issues.

All staff should:

- Utilise appropriate risk assessment and management approaches. This will mean devising arrangements for monitoring and ongoing contact to assess risk in timely manner.
- Be mindful of their 'Duty of Care' - 'the obligation to exercise a level of care towards an individual, as is reasonable in all circumstances, by taking into account the potential harm that may reasonably be caused to that individual or his property'.
- Have a working knowledge of an adult's right in law and the legal powers available for intervention. (A summary of these can be found in **Resource 1** on the WSAB website page)
- Utilise the Mental Capacity and Mental Health Act to identify when individuals are exposing themselves to risks without the ability to weigh up and use the relevant information to choose this. This is key to ensuring empowerment is at the heart of practice. Capacity to self-direct support and intervention should be central to practice in all cases.
- Where activity due to legal requirements results in enforced actions, such as cleaning and clearing due to environmental health issues, there is an expectation professionals work with best practice guidance in mind. As proposed in the practice tool "Working with people who Self-Neglect"[2] this should still be approached in a partnership manner with the individual creating as many opportunities as possible for them to be involved in the decision process. Professionals are advised to consult the guide for further guidance.

Information Sharing

Professionals can refer to the WSAB Information Sharing Protocol or the Safeguarding Practice guidance to review the seven golden rules of information sharing which apply in these situations.

Adults have the right to control the use of their personal information so consent to share should always be sought. However, the Data Protection Act 1998 does allow sharing of information when consent is not forthcoming in the adults 'vital interests', when:

- It is critical to prevent serious harm or distress or in life threatening situations
- To protect others who may be at risk from these behaviours

Professionals need to be mindful of the statutory duties and the requirement to be able to explain why the decision not to obtain consent was made. If it is necessary to share

[2] https://www.ripfa.org.uk/resources/publications/practice-tools-and-guides/working-with-people-who-selfneglect-practice-tool-updated-2016/

information without consent then the adult should be informed of the concerns and action to be taken, unless by doing so it increases the risk of harm.

When the adult is not able to give consent due to capacity issues then professionals may have a duty to share if it is deemed in their best interests as identified in the Mental Capacity Act. Gaps in information sharing are often identified in SARs and concerns must be escalated where there is no response.

Mental Capacity

Where there is a belief that the adult may not have the relevant mental capacity, they should be assessed under the Mental Capacity Act, making sure that sufficient information is provided to the adult to enable informed decision making. There should be proper assessment of capacity, including enabling the adult to demonstrate understanding, the weighing of potential risks, benefits and solutions, and making a choice including the ability to put decisions into effect. Best practice guidance encourages professionals to consider utilising the 'Articulate-Demonstrate' method (Naik et al, 2008[3]) of assessing as it helps identify when capacity to make a decision is present but the ability to carry out that decision is not.

Professionals must also be alert for signs of undue pressure or coercion being exercised, or of other circumstances preventing the individual giving free or informed consent. Professionals may need to find creative ways to address risks and needs as although interventions contrary to the adult's wishes may be supported in some situations by legislation, it must be necessary and proportionate.

Defensible Decision Making

The duty of care in relation to decisions made will be considered to be met where:

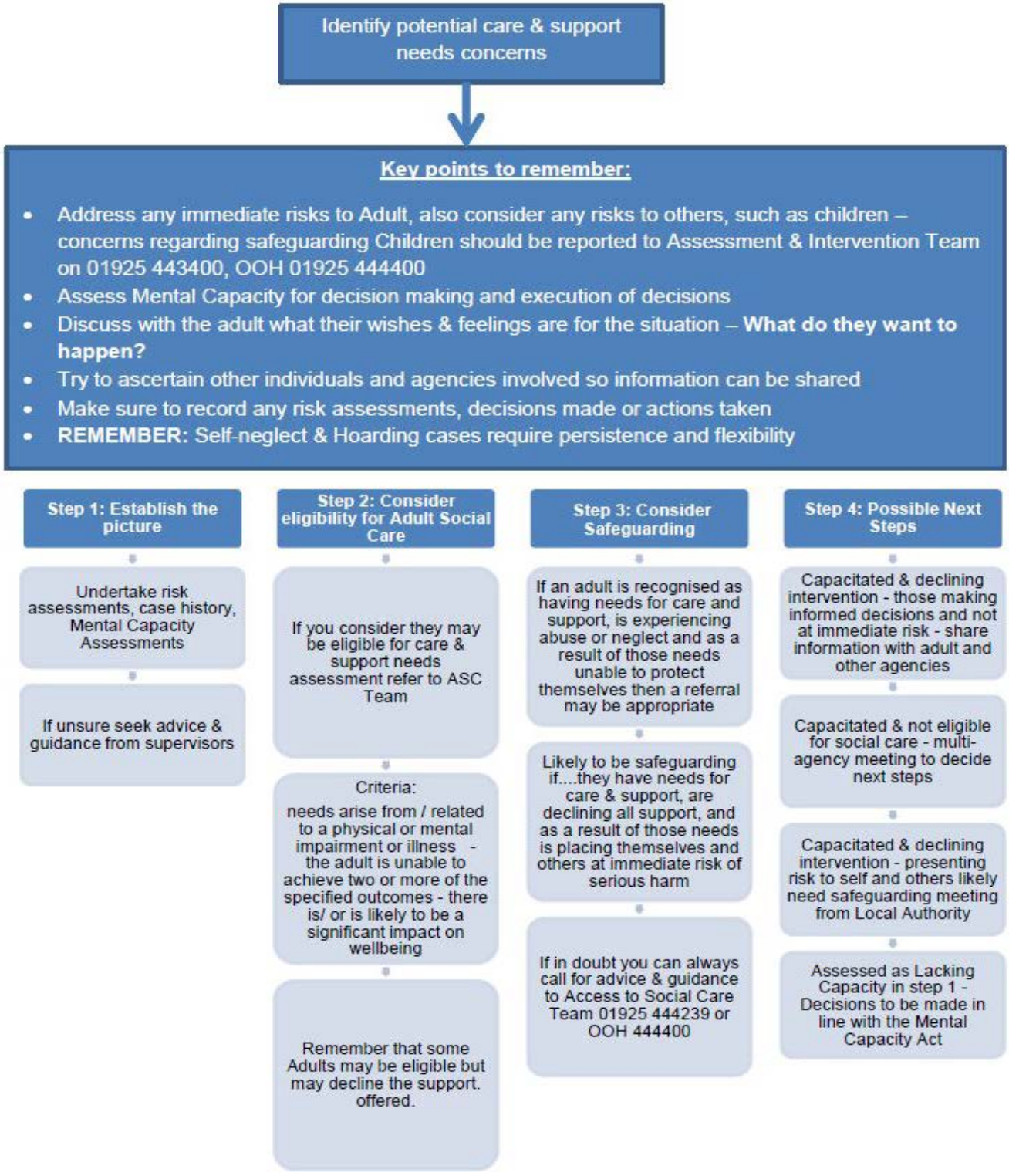
- All reasonable steps have been taken
- Reliable assessment methods have been used
- Information has been collated and thoroughly evaluated
- Policies and procedures have been followed
- Practitioners and their managers adopt an investigative approach and are proactive

Defensible decision making is making sure that the reasons for decisions, as well as the decision itself, have been thought through, recorded and can be explained.

[3] Assessing Capacity in suspected cases of self-neglect. Naik, Lai, Kunik and Dyer 2008, Journal of Geriatrics, accessible at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2847362/

WSAB Multi-Agency procedures & Professional Responses

In relation the Multi-Agency procedures the image below provides a brief overview of expectations. Further practice guidance can be found within the WSAB Multi-Agency Practice Guidance document in Section 23. Professionals should be prepared by their individual agency to recognise and respond to risk in practice. This document in no way seeks to replace internal practice guidance or training in relation to self-neglect.



Resolution of Disagreements and Complaints

The WSAB has a responsibility to monitor the effectiveness of agencies response to safeguarding matters locally, which can include reviewing practice in cases. There are two routes for professionals to raise concerns to the WSAB depending on the nature of the issue:

1. Inter-agency disputes regarding appropriate responses to cases – Agencies should follow the WSAB Escalation Procedure which can be accessed by clicking here.
2. Concerns in relation to Safeguarding Adult Review cases – if an adult dies or suffers permanent or serious harm as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked more effectively to protect the adult then agencies should submit the case to the board using the form in Appendix 2 of the SAR procedures which can be accessed by clicking here.

If an agency has a specific complaint regarding practice of another professional or agency then they should consider using the appropriate complaints process of that agency to flag such concerns. Exceptions to this would be when the issue relates to either of the processes described above.

Should agencies or professionals have disputes arise during the course of identifying & responding to an adult at risk of self-neglect & hoarding then it is imperative that these issues do not delay the provision of support or care to the individual. All agencies will be expected to resolve disputes in a timely fashion and ensure minimal impact on the individual.

Ending Involvement

Hopefully, involvement will end when the adult's situation has improved and in consultation with them or their representatives. However, in some cases no significant improvements will have been made.

The extent of efforts made or attempts to engage should be proportionate to the known presenting risks so it may be that after all reasonable and proportionate attempts to engage with a capacitated adult are exhausted, then it may be reasonable not to intervene further, as long as:

- No-one else is at risk
- Their 'vital interests' are not compromised (consider whether any immediate risk of death or major harm, a serious crime may have been committed, or whether they are being coerced)

Wherever possible there should have been an ongoing conversation with the adult in order for them to: weigh up the risks and benefits of options; be aware of the risk and possible outcomes; confirm the level of risk they are taking; and to offer advocacy or other appropriate support.

Where concerns continue any withdrawal of involvement must be done after discussion at an appropriate level and with appropriate involvement of the relevant agencies. In the case of withdrawal of a single agency, discussion is likely to be at a senior level within the organisation and where other agencies are involved, they must be involved or informed as necessary.

For those cases managed in a multi-agency environment including under the safeguarding procedures the decision to withdraw must be made after multi-agency discussion. This decision should also record any points agreed for onward monitoring and how a potential positive change in the adult's willingness to engage in the future may be responded to. Prior to withdrawal, risks should be reviewed in relation to safeguarding thresholds. Where there are grave and ongoing risks relating to an adult with care and support needs and the safeguarding process has confirmed that withdrawal is appropriate, the circumstances should be reported to the SAB.