

Dudley Safeguarding People Partnership

Thematic Safeguarding Adult Review

Self-Neglect

Learning Report

Independent Reviewer: Deborah Barnett May 2021

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Introduction

This is the Learning Report for the Thematic Safeguarding Adults Review (SAR) on Self-Neglect. The Executive Summary or full extensive Thematic SAR report is available to professionals on request.

The work of Safeguarding Adults Board over the next two decades to change this rapid decline in wellbeing is a great challenge. It is one that we can no longer afford to put sticking plasters over.

Dudley Safeguarding Adults Board sought to explore this in some detail in relation to five people considered to be self-neglecting prior to their early deaths and commissioned this review to help agencies working across Dudley to learn lessons from the circumstances surrounding the tragic deaths who had all experienced things within their lives that lead to them neglecting to care for themselves, resulting in their deaths between 2019 and 2020. All of them died before their time and in tragic circumstances.

The reviewer and all members of Dudley's Safeguarding Adult Board are grateful to those who knew or worked to support these individuals for their contribution towards the review, and for their insight towards what might have made a difference in these cases. To all of them and to all families and friends effected by the tragedies of these individuals, we want to extend our condolences and our sincere determination and commitment that this review, and the work that follows it, will improve the way services work in future with such vulnerable people. The report provides many challenges to all agencies within Dudley and the UK, in supporting people who no longer achieve self-care and who feel unable to access the required support to help them feel mentally and physically safe and well.

For the purpose of this review document 'Trauma' is used as a universal term to describe uncomfortable and adverse conditions a person has experienced and how this has impacted on them emotionally. Types of trauma could include loss, bereavement, poverty, discrimination, abuse, neglect, loss of power or control, loss of physical or mental wellbeing that affects self-confidence and self-esteem.

1. The Statutory Definition Of Self-Neglect Under The Care Act

1.1 The term self-neglect comes from the definition within the Care Act 2014. The author of this review regards the term as unhelpful, as 'self-neglect / self-harm' risks blaming the person for the coping mechanisms that they have developed (In the absence of structured response to trauma and loss).

1.2 Self-neglect seems to suggest that the person is making a decision not to care for themselves. Other labels of hoarding, homeless, misusing substances also lay the blame with the individual, as if somehow the person should simply be able to control themselves. What happens when significant life events such as the death of a close relative, abuse, neglect or trauma, affects a person so much that they can't deal with the emotional pain that they experience and they use survival mechanisms to get through the days? Drinking or taking drugs to drown out the pain, attaching themselves to objects instead of people - objects don't hurt them, feeling safe in open spaces as abuse or trauma occurred in an enclosed space? Practitioners were asked to consider responses from services through the eyes and feelings of the person considered to be self-neglecting.

1.3 Self neglect is not a 'lifestyle choice'. ¹(Braye et al) link the self-neglect causation to things such as loss, bereavement, trauma, abuse, threat. ²The Power, Threat Meaning Framework highlights and clarifies the links between wider social factors such as poverty, discrimination and inequality, along with traumas such as abuse and violence, and the resulting emotional distress or troubled behaviour, confusion, fear, or despair. This framework seeks to make sense of the experiences of people and how societal messages can increase feelings of shame, self-blame, isolation, fear and guilt.

1.4 If practitioners focus upon the label of **self-neglect**, **substance misuse**, **self-harm**, **suicidal ideation**, **hoarding**, then they will focus upon a cure being to clean the property, to stop the self-harm, or to prevent the substance misuse. This means that agencies are focussing on removing the very coping mechanisms keeping people safe from the real dangerous matters (Trauma, loss, bereavement, social isolation, fear and poverty) that cause mental and physical ill health. These coping mechanisms may have become part of the problem, but to the person they are survival strategies that have kept them alive for a number of years. People who have been hurt by people shrink away from people to prevent further harm. If the perception is that services pose a risk, then they will shy away from services. Our safeguarding challenge is to address the cause of self-neglect (What happened to the person). Understanding trauma and how it affects a person is the key.

2. The Statutory Definition Of Safety And Wellbeing Under The Care Act 2014

2.1 Safeguarding means determining whether a person is safe and well and if not seeking what that person requires to achieve safety and wellbeing

2.2 We can use the safeguarding and wellbeing principles as check lists to our daily work with individuals. When working with someone said to be self-neglecting before you conclude any care and support arrangements you will need to consider:

2.3 Safeguarding principles in practice:

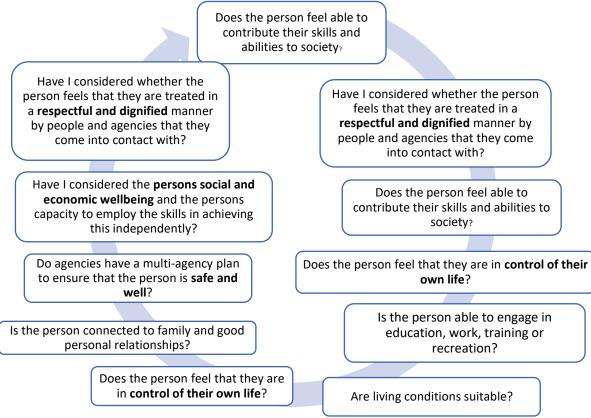
Have I empowered the person:	 Asked them what they want to stay safe and well, Understood what happened to them to cause them to feel so bad about themselves, Provided solutions to build self-confidence, self-worth and self-esteem, Help with positive connections to people and prevented retraumatisation? Have I considered whether the persons adverse experiences are affecting their ability to employ self-care skills and therefore capacity to make decisions about care and support? 	
Have I risk assessed the safety and wellbeing of the person and prevented escalation of safety and wellbeing concerns?	Has someone been consistent in establishing engagement with the person?	
Have I protected the person from the impact of trauma and re-traumatisation, rejection, further loss, blame or feelings of guilt?	Do I understand and build upon the persons strengths?	
Have I responded in a proportionate	what was ruled out and why?	
way to the risks to the person and others,		
Have I gathered a multi-agency	to have a collective perspective of risk and a plan to keep the	
partnership meeting	person safe and well?	

¹ Self-neglect policy and practice: key research messages (scie.org.uk)

² Introduction to the PTMF | BPS

Have I held agencies accountable	for capacity assessments, risk assessments, communication	
	plans, support pathways and routes to build the persons self-	
	confidence and self-esteem?	

2.4 Wellbeing principles in practice:



2.5 How to stay safe and well

To support safety and wellbeing we need to address the impact of trauma at the time it is experienced by the person / child. Mental and physical wellbeing are not exclusive to each other, they hold each other's hands up, but also pull each other down causing combined mental and physical deterioration when trauma is experienced. The impact of trauma can cause a person to utilise coping or survival strategies that result in self-neglect. We need to work closely to develop an understanding and recognition of trauma responses displayed by the person. We need to support the person in feeling safe from the threat of further trauma.

Addressing trauma creates resilience for the future. Less homelessness, less mental ill health, and reduction in physical ill health, less hoarding, less criminal activity and a solution lies in understanding a person's experiences.

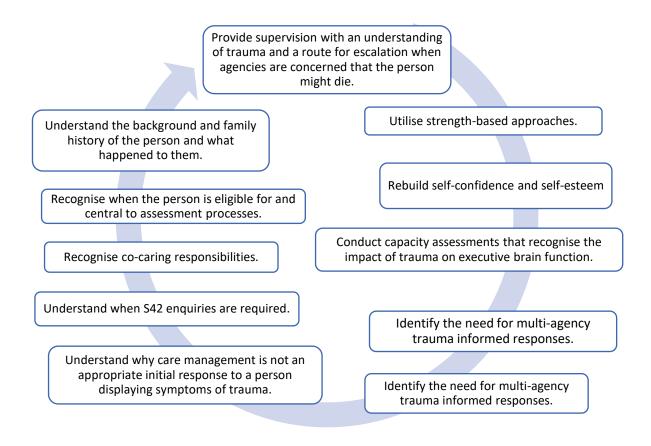
The effects of trauma and associated survival strategies, impacts upon a person's physical, emotional and mental wellbeing. It is the view of this author that trauma informed approaches need to be located within wellbeing safeguarding responses. Research identifies a number of factors that are repeatedly raised in Safeguarding Adults Reviews relating to persons said to self-neglect and the current manner in which agencies respond.

We must endeavour to use trauma informed responses to recognise and understand the lack of ³personal power and effect, level of threat and the negative interventions a person said to be self-neglecting experiences on their journey through services. This requires a move from care management to muti-agency planning and support for an identified agency / person who will engage and develop the trust of

³ Power Threat Meaning Framework | BPS

the person. Once this is established essential contact with other agencies can be achieved via the trusted person.

2.6 Key considerations include being able to:



3. Cases Reviewed

3.1 Dudley Safeguarding Adults Board referred five deaths of individuals who were regarded to be selfneglecting prior to their deaths occurring between 2019 and 2020.

3.2. All five people were considered difficult for agencies to engage with and either refused or cancelled services. The five people will be referred to throughout this review as L, K, H, P and W.

3.3 L - L was dependent upon Diazepam and alcohol, her weight was very low, there was little evidence of food in her property and she was not taking essential medication. Domiciliary care was commissioned after repeated hospital admissions. Care services were to provide food and to ensure that medication was taken. L regularly cancelled her care provision. Following several failed attempts to contact L a safe and well check was conducted, L was found dead at home.

3.4 **H** – H was caring for her husband who was also considered to be self-neglecting. Police report a history of domestic abuse. H considered herself to be in danger from her husband, reporting this to the ambulance service in 2017. Previous 999 calls identified H as the aggressor. On multiple occasions H complained to her GP and the local authority that she was struggling to provide care for her husband, who it was thought may have had Dementia. H's husband was reported to not have washed or changed his clothing for over two years, his toe nails had grown through his socks and he informed ambulance services that he had not been seen by health care professionals in the last 18 years. H had very poor tissue viability presenting on two occasions at hospital with moisture legions and blackening skin. H discharged herself against advice. Neither H nor her husband appeared to be eating well. The property was reported to be in a poor state with H lying on clothes on the kitchen floor. Ambulance staff reported

that in the kitchen there was cat faeces 'all over the floor', rat droppings and dead flies, old food and discarded coffee / tea cups. A week prior to her death H had been admitted to hospital with diarrhoea and vomiting but self-discharged.

3.5 **K** - K was diagnosed with chronic kidney disease attributed to excessive alcohol consumption. K was not attending to his health needs. His property was described to be in a poor state and he was not changing his clothing. It was reported that K had regular visits from his sister and nephew who brought him food. K visited his sister who lived on the same street. After a number of failed attempts to make contact K was found dead at home.

3.6 **P** - P was not known to services prior to 2020. In January 2020 the ambulance service were called to P's property as he was suffering from chest pains. The ambulance team were concerned that P was living alone, alcohol dependent, jaundiced with a distended abdomen and was in organ failure. P refused to eat or drink and also refused hospital treatment. P died a few days later.

3.7 **W** – W had a diagnosis of type 2 Diabetes and was insulin dependent. W's daughter had a history of domestic abuse, but this did not appear to have impacted upon W. After a prolonged hospital stay following a hernia operation W's GP visited her on six occasions between March and June 2019. W's stoma was bleeding, she had an infected wound, her limbs were swollen following a fall and the GP was concerned about her significant health deterioration. In May 2019 an out of hours GP and the ambulance service noted W to have symptoms of Sepsis. W refused to go to hospital and was deemed to have capacity to make this decision. There were concerns that W's husband was struggling to provide care for her in between her care visits. W was not eating and ambulance staff were concerned and advised her that she may go into hyper shock which could result in death. W stated that she didn't care. W died within approximately one week of the concerns being raised.

4. Learning Points And Key Findings

Outcome 1: Formulation - A Persons Own Story

The review found that some agency had some details about the individual's life and what was perceived as their care and support needs, but this had not been formulated in a multi-agency response to support the individuals. It is important to recognise getting the persons story, connections, life events, how they have coped and what they want to stay safe and well. The question 'What happened to you?' is of central importance. The aim is to support the person to regain confidence, self-esteem and self-worth and eventually the ability to relinquish the survival strategies (Substance misuse, hoarding, self-neglecting, under / over eating etc) in favour of better serving strategies.

Care Management is not an appropriate initial response to a person self-neglecting and there is no evidence from Safeguarding Adults Reviews or the thematic review that this model works. A trusting relationship will need to develop with a key person identified to help to re-engage the person with community activities, develop friendships and build self-confidence and self-esteem. This relationship can be used to support the person to develop trust in other agencies by ensuring responses are trauma informed. More information is known about L and H and yet there is nothing to suggest that any of the interventions were strength based

Supporting individuals to rebuild self-confidence and self-worth after trauma, loss, abuse or neglect. Understanding a person's experiences and life narrative is key to understanding the solutions.

Outcome 2: Safeguarding And Wellbeing Principles

In summary there is little evidence of the safeguarding and wellbeing principles being applied in practice (See 3.3 and 3.4 of Executive Summary/Thematic SAR Report)

The safeguarding and wellbeing principles might serve as checklists for all agencies to use in relation to people who self-neglect. Consider the persons journey through life and the adversities that they have faced, the power they feel that they have in their life and the meaning that they derived from the adverse

encounters or traumas.

- What might a person so traumatised need from services to re-engage with people, when people have been the source of their pain?
- What messages do agencies need to give when interacting with the person who is traumatised?
- How can the drip feed of messages and interventions change to provide positive feedback, positive community contribution and development of self-worth and self-esteem?
- What strengths does the person have that can be used to help them to obtain the positive feedback?
- Consider routes and pathways to achieving the right support and care.

Recommendation

- Adult Safeguarding Board to consider reviewing their Multi-Agency Risk Management (MRM) process
- To gain assurance that key person is identified within the care records for people who are selfneglecting

Outcome 3: Eligibility Pathways & Criteria

There was a lack of understanding when the person is eligible for and if universal services are not maintaining a person's safety (Safeguarding Principles apply) and wellbeing (Wellbeing Principles apply) then the local authority need to provide oversight and guidance to ensure that the person remains safe and well.

The refusal of life saving treatment, food and drink sometimes described as passive suicide. In these situations where there is concern that the death is imminent, one week is too long to wait to assess capacity regarding critical care and support that is being refused. There should be urgent pathways to assess risk and need.

Practitioners identified that they had some or little understanding of the Eligibility criteria for statutory assessment and needs assessment which needs to be considered at the earliest opportunity. And the review identified in several cases there was drift and delay.

Recommendation

- Eligibility criteria for statutory assessment needs to be better understood by all agencies and to have an escalation procedure when practitioners feel that outcomes are not achievable/achieved
- Pathways mapped in relation to people considered to be self-neglecting need to include consideration of critical risks when practitioners are concerned
- Briefing Paper to be developed to ensure that frontline practitioners understand the Eligibility criteria for statutory assessments

Outcome 4: Safeguarding Risk Assessment and Decision Making

Consistent safeguarding risk assessment and consideration of the safeguarding and wellbeing principles should be embedded into frontline practice.

All agencies need to recognise and should be empowered to appropriately challenge decision making relating to safeguarding a person. Where there are gaps in knowledge such as what the risks are, whether the person is capacitated to make these decisions, whether they have been affected by trauma, whether there are other caring responsibilities affecting them, whether the person is feeling threatened, whether they are afraid of service intervention, what happened to the person and how to engage with the person, agencies need to get together and explore these gaps at the earliest opportunity.

Section 42 Enquiries

In all cases person had limited engagement with services, this is an indication that the person is concerned

about contact with others and a trigger for consideration of trauma affecting that person. This should have led to a multi-agency planned response with a lead agency identified. The response cannot close until the person feels safe and well.

Multi-Agency Safeguarding Enquiry

It was identified by this review that multi-agency enquiry and support process was not always timely an early response is required to safeguarding a person considered to be self-neglecting. Single party engagement is required to develop trust and restore confidence that agencies are not going to do anything that the person perceives as a threat, or harmful to them. Once this relationship has formed it can be used to introduce other agencies for support when the person feels able.

Multi-agency information sharing and planning is required when a person is not engaging well with services.

Recommendation

- All enquiries should be the person centred and include planned capacity assessments, communication and support plans for the agency engaging with the person and connecting with the person (Including advice and support from other agencies regarding capacity assessment). It is important that these enquiries are not intrusive and that they are sensitively conducted by someone who can seek to understand and demonstrate compassion for the person who has experienced trauma.
- To consider utilising the Mental Capacity Assessment paperwork for complex self neglect cases to enable all frontline practitioner to be recording in a consistent manner to ensure they are recording with a legal framework
- To Review MDT paperwork

Outcome 5: Mental Capacity and executive functioning

Although mental capacity assessment had been completed in some cases it was not clear if the practitioners involved in the cases had conduct capacity assessments that recognised the impact of trauma on executive brain function. Part of the capacity assessment is to determine whether the person is able or unable to employ the skills of self-care (S4.21 MCA codes of practice). But records did not often demonstrate that a person is unable to employ self-care skills. Consideration is then given as to whether the reason that the person cannot maintain self-care skills is as a result of trauma, anxiety, mental ill health or other impairment of, or disturbance in the functioning of the mind or brain.

If the person cannot demonstrate the skills of self-care as a result of being unable to manage order, prevent compulsive or impulsive responses, being unable to initiate tasks etc. and that can be directly attributed to the impairment of, or disturbance in the functioning of the mind or brain then they have identified needs that are now required to be met. They are not self-neglecting as much as unable to care for themselves. The responsibility of all agencies is to empower that person by supporting the development of positive feedback that will result in self-esteem and self-confidence being restored and the person regaining trusting relationships with others.

Recommendations

 Agencies including Health, Mental Health services and community services, Housing and the local authority will need to be aware of the importance of determining whether executive brain function is affected by a person's adverse experiences. Referrals to the Court of Protection are required to elicit case law that provides guidance **Outcome 6: Think Family** (Practice with the individual adult in their social situation: Whole Family Approach)

In three of the cases there was family involved there was evidence of assessment for the individual but consideration for the other family members had not been considered.

In case H whole family approach needed to be adopted and consideration given to whether there are cocaring responsibilities that are not meeting need. Domestic abuse (Including that of neglect) needs to be considered and ruled in / out. In situations where safety and wellbeing are not being maintained by universal services, statutory assessment is required.

Recommendation

• A whole family approach to assessment and co-caring responsibilities to be developed. If a person is identified as meeting a need and safeguarding concerns have been raised,

Outcome 7: Practice with the individual adult in their social situation: Trauma Informed Practice

It was found in all cases reviewed that the individuals lacked motivation, struggle to initiate tasks, found it difficult to engage with others, struggled to order and prioritise things, act compulsively or impulsively. And this lack of self-worth and self-esteem causing a person to self-neglect, by nature, means that the person was not accepting care and support.

In some of the cases the person was between agencies, sending referral letters, switching through a variety of social workers in different teams and expecting contact, motivation, maintenance of services and this may have impacted on the person willingness to accept support.

The narrative of agencies conveyed to the person desperate for a solution can add to the experience of trauma: Not eligible, not motivated, to attending, not engaging, not cooperating.

Initial contact should have been coordinated agreement about how to remove pressure and threat from the person, whilst one identified person creates engagement and formulates the person's story. Agencies are then needed to support that one person in eliciting the information that they require. This includes what that person wants to stay safe and well and whether they are capacitated to make each decision.

During the practitioner events it was felt that Trauma informed practice that recognises 'Power, Threat and Meaning'. To consider the power that the person perceives themselves to have in life and interactions, the threats that they feel they face and the messages that interactions and interventions give them / tell them. Personal contact and personal stories are important from the single point of contact through assessment and intervention.

Recommendation

- All agencies need to consider whether the impact of trauma is affecting a person's responses and preventing them from being able to self-care
- All Agencies should work to support trauma informed intervention at an early stage The nature of trauma resulting in self-neglect
- Adult Safeguarding Board to consider sourcing training for multi-agency trauma informed practice

5. Recommendations

Recommendations		Linked Outcome
1.	To review and refresh the MRM Procedure	Outcome 1/2
2.	Eligibility criteria for statutory assessment needs to be better understood by all agencies	Outcome 3
3.	Pathways mapped in relation to people considered to be self- neglecting need to include consideration of critical risks when practitioners are concerned	Outcome 3
4.	Escalation procedure when practitioners feel that concerns remain	Outcome 4
5.	All S42 enquiries and assessments should be person centred and include planned capacity assessments, communication and support plans for the agency engaging with the person and connecting with the person (Including advice and support from other agencies regarding capacity assessment). It is important that these enquiries are not intrusive and that they are sensitively conducted by someone who can seek to understand and demonstrate compassion for the person who has experienced trauma.	Outcome 1/2/4
6.	To consider utilising the Mental Capacity Assessment paperwork for complex self-neglect cases to enable all frontline practitioners to be recording in a consistent manner to ensure they are recording with a legal framework	Outcome 4
7.	All agencies including Health, Mental Health services and community services, Housing and the local authority will need to be aware of the importance of determining whether executive brain function is affected by a person's adverse experiences	Outcome 5
8.	Referrals to the Court of Protection are required to elicit case law that provides guidance	Outcome 5
9.	A whole family approach to assessment and co-caring responsibilities to be developed. If a person is identified as meeting a need and safeguarding concerns have been raised	Outcome 6
10.	All Agencies should work to support trauma informed intervention at an early stage	Outcome 1/7