Self-neglect and mental capacity: the evidence-base from safeguarding adult reviews

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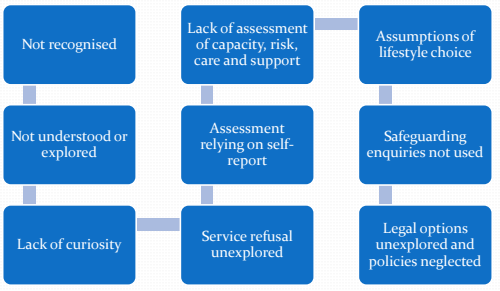
The evidence-base for working with adults who self-neglect

- Learning from individual safeguarding adult reviews
- Analysis of 500+ reviews in England
- Much smaller numbers in Wales and Scotland
- National SAR Analysis April 2017 – March 2019
- 98% response rate from SABs
- 231 SARs in the sample
- 45% focus on self-neglect
- Self-neglect the most frequent type of abuse or neglect reviewed

Self-Neglect Definition

- lack of self-care – neglect of personal hygiene, nutrition, hydration, and health, thereby endangering safety and well-being, and/or
- lack of care of one's environment – squalor and hoarding, and/or
- refusal of services that would mitigate risk of harm.
- A variety of key episodes – fire deaths, drugs and alcohol abuse, infections from poor tissue viability, impact of mental distress or learning disability, multiple exclusion homelessness, untreated diabetes …

National Analysis Findings



Direct practice – best practice

- Person-centred, relationship-based practice
- Professional curiosity (history)
- Assessment of care & support, and mental health
- Transitions – opportunities not cliff edges
- Assessment & review of risk and capacity
- Family involvement (think family)
- Availability of specialist advice
- Legal literacy
- Balancing autonomy with a duty of care

Inter-organisational environment (team around the person) – best practice

- Guidance on balancing autonomy with a duty of care
- Information-sharing & communication
- Working together on complex, stuck and stalled cases
- Use of multi-agency meetings and safeguarding enquiries
- Clear roles and responsibilities (lead agencies and key workers)
- Shared record-keeping

Organisational environment – best practice

- Development, dissemination & review of guidance
- Clarifying management responsibilities and oversight
- Staffing, supervision, support & training
- Recording standards
- Commissioning & contract monitoring
- Culture of openness, challenge and escalation

SAB governance – best practice

- Audit & quality assurance of what good looks like
- Multi-agency training
- Review of management of SARs
- Workplace as well as workforce development
- Continual review of outcome of recommendations
- Use of SARs to inform policy development, practice audits and training

Discussion Point One

- Where do we align or get close to the evidence-base?
- What has helped us to do this?
- What obstacles and barriers have hindered getting close to the evidence-base?
- What further changes in systems, policy or practice could enhance the enablers of effective practice and address barriers to improvement?

Voices of Experts by Experience

- When asked what he needed, Terence replied: "Some love, man. Family environment. Support." He wanted to be part of something real, part of real society and not just "the system". (reported in a thematic review on people who sleep rough, Worcestershire SAB (2020)).
- From the Leeds Thematic Review (2020):
  - "I lost everything all at once: my job, my family, my hope."
  - "Without [this help in Leeds], I'd already be dead. I've no doubts about that. If the elements hadn't got me, I would have got me. Sometimes I have rolled up to this van in a real mess and they have offered help and support and got my head straight."
- Ms I's partner commented (Tower Hamlets SAB (2020) Thematic Review):
  - At times "she could not help herself" because of the feelings that were resurfacing; access to non-judgemental services was vital and helpful, and that support is especially important when individuals are striving to be alcohol and drug free. It was during these times that stress, anxiety and painful feelings could "bubble up", prompting a return to substance misuse to suppress what it was very hard to acknowledge and work through.

Poem Extract (in full in Preston-Shoot, M. (2021) *Adult Safeguarding and Homelessness: Experience-Informed Practice*. Local Government Association)

From a friend to an imposter, you started to be
I tried to ignore you and ask you to leave
You started to control me and take over my mind
The hope of you leaving was now left behind
I started to believe you wanted me dead
Still, I turn to you daily for relief from my head
I thought I had beaten you time again
But you wanted to kill me, you are here till the end
I pleaded and begged, I got down on my knees
I didn't understand that I had a disease
It would take more than my willpower to keep you at bay
I needed support to get through everyday

What people with lived experience say about working with them

- *Engagement* – recognise that people may be wary of professionals and services, possibly due to past experiences of institutions and the care system; appreciate that individuals may feel alone, fearful, helpless, confused, excluded, suicidal and depressed, unable to see a way out.
- *Professional curiosity* – "I was not asked 'why?'" There is always more to know. Experiences (traumas) had a "lasting effect on me." "Appreciate the beginning of the journey." What has happened to you?
- *Partnership* – "work with me, involve me, and support me." "Keep in touch so that we know what is going on." Help with form filling, bank accounts and other practicalities.
- *Person-centred* – see the person and, where necessary, adapt our approach; "people did not see beyond the sleeping bag"; challenge misconceptions of people who self-neglect and any evidence of assumptions (unconscious bias) that someone may be undeserving or making a lifestyle choice.
- *Assessment* – what does this individual need? Do not assume or stereotype. Explore unwillingness and/or inability to engage.
- *Language* – be careful and respectful about the language we use; words and phrases can betray assumptions. For example, who is not engaging? What does substance misuse imply?

Learning from the voices of lived experience

- Seeing the whole person in their situation
- A trauma-informed, whole system response to the person in context
- Being careful and care-ful when thinking about removing a coping strategy
- In the context of people's experiences of self-neglect, the notion of lifestyle choice is erroneous
- Tackling symptoms is less effective than addressing causes.
  - Attempting to change someone's behaviour without understanding its survival function will prove unsuccessful. The presenting problem is a way of coping, however dysfunctional it may appear. Put another way, individuals experiencing self-neglect are in a "life threatening double bind, driven addictively to avoid suffering through ways that only deepen their suffering."

Salford SAB: SAR Eric

- Eric, aged 81, died in hospital in October 2019. Since mid-September he had consistently refused food, water, personal care and treatment. Coroner ruled that the medical cause of death was starvation.
- **The case raises the dilemma of autonomy versus a duty of care, and the challenge of differentiating between decisional and executive capacity, and of assessing (fluctuating) capacity when the person does not easily engage**
- **Consider legal options explicitly throughout management of high risk cases.**
- Develop a culture where escalation and challenge is seen as central to best practice
- Insufficient familiarity and/or use of self-neglect policy
- Insufficient use of whole system meetings
- **Take time to ensure care-givers understand the support that can be offered and acknowledge the stress and anxiety they carry**
- Debrief staff and offer support when cases of high risk result in a person's death

Croydon SAB: Duncan

- Duncan was born on 29th April 1983 and died at the age of 35. He had fallen from a building and cause of death was regarded as a possible suicide.
- Records indicate that he had been adopted at the age of 7 but later his relationship with his adoptive parents is said to have broken down. He was apparently unwilling to speak about his life.
- Duncan wished to live independently but this option was not pursued. How well are we working with people who present with multiple needs and who find it difficult to engage? Are they not engaging with us or are we not engaging with them? How well do we know the people we are working with? Is there sufficient focus on the impact of trauma and adverse experiences? (**MSP**)
- Duncan had several admissions under section 3 mental Health Act 1983 but there is no reference to a section 117 after-care plan. Are we assured about after-care planning for people detained under longer-term sections in MHA 1983? Duncan was ultimately discharged from the CPA without an updated **risk assessment** and with ongoing mental health concerns.
- Duncan did not receive a section 9 Care Act 2014 **assessment for care and support needs**.

Haringey SAB – Thematic Review Homelessness

- Insufficient use of **interpreters** and **advocacy** (see also MS, City of London and Hackney)
- Insufficient **curiosity** of backstory and misunderstanding of race/culture/ethnicity
- Lack of **mental capacity assessments** and especially a focus on executive functioning

The tricky concept of lifestyle choice

- SARs tell us we are quick to assume capacity, respect autonomy (and walk away) – "it's a lifestyle choice"
- But life stories tell us otherwise:

I used to wake up in the morning and cry when I saw the sheer overwhelming state… My war experience in Eastern Europe was scary, but nothing compared to what I was experiencing here.

Well I don't know to be honest. Suddenly one day you think, 'What am I doing here?'

I got it into my head that I'm unimportant, so it doesn't matter what I look like or what I smell like.

Your esteem, everything about you, you lose your way … so now you're demeaning yourself as the person you knew you were.

I put everyone else first – and that's how the self-neglect started.

Challenging the dichotomy

Is it really autonomy when …	Is it really protection when …
• You don't see how things could be different	• Imposed solutions don't recognise the way you make sense of your behaviour
• You don't think you're worth anything different	• Your 'sense of self' is removed along with the risks: "*hoarding is my mind*"
• You didn't *choose* to live this way, but adapted gradually to circumstances	• You have no control and no ownership
• Your mental ill-health makes self-motivation difficult	• Your safety comes at the cost of making you miserable
• You have impairment of executive brain function	

A more nuanced ethical literacy

Respect for autonomy entails	Protection does not mean
Questioning 'lifestyle choice'; respectful challenge; care-frontational questions	Denial of wishes and feelings
Dialogue towards positive autonomy; maximise ability to see options and make care-ful choices	Removal of all risk

Autonomy does not mean abandonment
Protection entails proportionate risk reduction

Mental Capacity Act 2005: a reminder

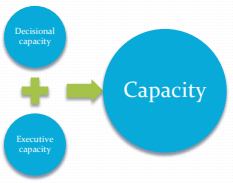
Five key principles

- Assume a person has capacity unless proven otherwise = presumption of capacity: adult has right to make decisions, unless incapacity proven
- Do not treat people as incapable of making a decision unless all practicable steps have been tried to help them = right to support to maximise capacity to make own decisions
- A person should not be treated as incapable of making a decision because their decision might seem unwise = not exactly a right to make eccentric or unwise decisions
- Best interests duty for decisions taken on behalf of people lacking capacity
- Least restrictive intervention to preserve basic rights and freedoms

- Mental capacity in the literature involves

  Not only
  - the ability to understand and reason through the elements of a decision in the abstract

  But also
  - the ability to realise when a decision needs to be put into practice and execute it at the appropriate moment – the 'knowing/doing association'
- Frontal lobe damage may cause loss of *executive brain function*, resulting in difficulties:
  - Selecting relevant information and using or weighing it in the right context, in the moment
  - And therefore in planning, problem-solving, enacting a decision in situ



Putting this understanding into practice

Decision-making difficulties may be masked by	Capacity assessment to take account
Articulate use of language; verbal reasoning skills; high perceived self-efficacy	Articulate and demonstrate models; the person in context; real world behaviour
Resulting in decision-making that is "good in theory, but poor in practice"	*GW v A Local Authority [2014]* EWCOP20

National guidance (NICE 2018) and Case Law on Executive Functioning

Practitioners should be aware that it may be more difficult to assess capacity in people with executive dysfunction – for example people with traumatic brain injury. Structured assessments of capacity for individuals in this group (for example, by way of interview) may therefore need to be supplemented by real world observation of the person's functioning and decision-making ability in order to provide the assessor with a complete picture of an individual's decision-making ability.

Decision-making and mental capacity guidance (para 1.4.19)

- Sunderland City Council v AS and Others [2020] EWCOP 13
  - Importance of real world observation to obtain a full picture.
- A Local Authority v AW [2020] EWCOP 24
  - Ability to think, act and solve problems include the functions of the brain which help us to learn new information, remember and retrieve the information we've learned in the past, and use this information to solve problems of everyday life.

Signposts to best practice

- In cases of fluctuating capacity, the courts and NICE have advised taking a long-term perspective on someone's capacity rather than simply assessing the capacity at one point in time.
- Carol SAR (Teeswide SAB): *the concept of "executive capacity" is relevant where the individual has addictive or compulsive behaviours. This highlights the importance of considering the individual's ability to put a decision into effect (executive capacity) in addition to their ability to make a decision (decisional capacity).*
- Howard SAR (Isle of Wight SAB) and the Ms H and Ms I SAR (Tower Hamlets SAB) highlight people who are driven by compulsions that are too strong for them to ignore. Their actions often contradicted their stated intention to control their alcohol use: i.e. they were unable to execute decisions that they had taken.
- Ruth Mitchell SAR (Plymouth SAB): *To assess Ruth as having the mental capacity to make specific decisions on the basis of what she said only, could produce a false picture of her actual capacity. She needed an assessment based both on her verbal explanations and on observation of her capabilities, i.e. "show me, as well as tell me". An assessment of Ruth's mental capacity would need to consider her ability to implement and manage the consequences of her specific decisions, as well as her ability to weigh up information and communicate decisions.*

Liverpool SAB – SAR Hazel

- Hazel died age 55. She had a medical history of alcohol-dependence and hepatitis, cirrhosis of the liver, diabetes and hypertension.
- Hazel's property was in a poor state of repair, with accumulated rubbish. She was lying in her own faeces. Hazel had refused care, support and treatment. She had previously been discovered in a similar state in November 2020.
- She received support from her father. **Do we think family?** She had one son. We know little about her life , her mental distress, to help us understand the challenges she faced. **Do we know the backstory?**
- She did not always keep appointments for her various health issues. Services reported difficulty in making contact with her. **Do we reach out?**
- When Hazel declined assessments from Adult Social Care, the provision in Section 11 Care Act 2014 should have been considered
- Making Safeguarding Personal should include **concerned curiosity**, attempting to establish a relationship.
- Was consideration was given to **executive functioning**, the impact of her alcohol misuse/dependence on her mental capacity?

Learning from Keith's story about hoarding

- You will find Keith's story on you tube.
- The key messages are:
  - Find the back story – for Keith his hoarding was to keep people away
  - Address the back story and not just the presenting problem
  - Recognise the barriers to change – fear, shame
  - Go at the pace of the individual – their journey in their time also
  - Work collaboratively
  - Be careful about the language used and do not make assumptions
  - Do not touch possessions without consent

But can we practise in this way?

- We have a strong evidence base from the research; we know what good looks like in working with people who self-neglect
- There are challenges in putting this into practice
- Take a moment to consider your own workplace:
  - What supports you to achieve best practice in self-neglect?
  - What hinders you?
- Make a note and share your experience of work

Returning to human stories

- Duncan (Croydon SAB) does not appear to have had any involvement with, or intervention from substance misuse services. How well do services respond to and work with individuals with both mental health and substance misuse problems? **How well do services work together? No multi-agency risk management meeting was convened.**
- Child/Adult Y and Child/Adult Q (Havering SAB) - lack of use of **adult safeguarding procedures. Multi-agency and multi-disciplinary meetings were held** but plans were insufficient to reduce the risks and ensure collaboration across services.
- Haringey SAB Thematic Review – absence of **multi-agency risk management meetings**. Safeguarding concerns referred but **no safeguarding enquiries**.

MS: City of London & Hackney SAB

- MS died, aged 63. Cause of death was acute myocardial infarction, coronary artery atherosclerosis and aspiration pneumonia. He died at a bus stop where he had been living.
- MS was Turkish (Kurdish ethnicity) with limited understanding of English and a history of homelessness, self-neglect and substance abuse. He had returned to the bus stop where he eventually died at the end of May 2019, having spent the previous five months in a nursing home. When that placement came to an end he was offered a hotel room but declined. He said that "something brings [me] back to the bus stop."
- There were discussions on whether and how to use anti-social behaviour powers, and mental capacity and mental health legislation, in order to safeguard his health and wellbeing, and to address expressed concerns from local residents. No effective means of resolving the situation was found before he died. **Legal literacy.**
- When practitioners could not agree on whether he had capacity, they walked away, unable to reach a decision. **Those involved did not work together to agree the approach on mental capacity decision-making.**
- **Referred adult safeguarding concerns did not lead to a section 42 enquiry. Local authority decision-making was not challenged.**
- **No multi-agency, multi-disciplinary risk management meeting was convened.**

Kirklees SAB Adult N

- Adult N died in his flat, aged 41. Cause of death was acute fatty and chronic alcoholism. Adult N had a history of homelessness, self-neglect and substance (alcohol) abuse.
- During this time he had experienced periods of homelessness, living in a car, in woodland or occasionally hotels. Often he was found living in insanitary conditions, self-neglecting, unresponsive and intoxicated.
- There were assumptions about lifestyle choice and insufficient curiosity about the background.
- **There were no multi-agency risk management meetings despite a repeating pattern of attendances at A&E and concerns expressed by paramedics and the police. There was no lead agency or key worker appointed.**
- **Services did not work together, for example in-reach and outreach mental health and substance misuse agencies. There were few referrals of adult safeguarding concerns and no section 42 enquiry.**

Liverpool SAB: SAR Hazel

- Hazel sometimes refused consent for information about concerns to be shared. The Data Protection Act 2018 permits information-sharing without consent to safeguard an adult at risk **(legal literacy)**
- No clear pathway into **multi-agency meetings** when there is a risk of significant harm that requires a multi-agency response?
- Services worked in silos.
- No **section 42** safeguarding referrals of concern.

Does this happen here?

- Do you recognise any of these organisational features in your own work environment?
- Please use the chat box to share any examples of how your agency supports good self-neglect practice

Returning to Human Stories

- Croydon SAB – Duncan. Working with people who self-neglect, who have longstanding challenges involving mental health, substance misuse and challenging behaviour, is itself challenging. How well **support**ed are practitioners and operational managers for working with people who present a range of complex problems?
- Havering SAB Ms A – How supportive are we of practitioners who knew the person well and who have been profoundly affected by their death? (**staff support**)
- Havering SAB Child/Adult Y and Child/Adult Q – shortage of placements for your people and young adults with complex needs and challenging behaviours (**commissioning**)
- Haringey SAB Thematic Review – lack of familiarity with, and use of **self-neglect policies and procedures**
- Liverpool SAB SAR Hazel – **senior managers unsighted on the risks and concerns**

Isle of Wight SAB – Howard (2018)

- Homeless single adult without local family support
- Impact of adverse life events
- Longstanding alcohol misuse and physical ill-health
- Hospital and prison discharges to no fixed abode
- Police and ambulance crews concerned about risks of financial and physical abuse, and his self-neglect
- Refused housing as not regarded as in priority need
- **No wet hostel available – commissioning (shortage of providers, especially for complex cases)**
- Referrals to adult safeguarding do not prompt multi-agency meetings or investigation; no completed Care Act 2014 care and support assessment
- No lead agency or key worker; no risk assessment or mitigation plan

The core dilemma

- "The fact is that all life involves risk, and the young, the elderly and the vulnerable are exposed to additional risks and to risks they are less well equipped than others to cope with. But just as wise parents resist the temptation to keep their children metaphorically wrapped up in cotton wool, so too we must avoid the temptation always to put the physical health and safety of the elderly and the vulnerable before everything else. Often it will be appropriate to do so, but not always. Physical health and welfare can sometimes be bought at too high a price in happiness and emotional welfare. The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid in order to achieve some other good – in particular to achieve the vital good of the elderly or vulnerable person's happiness. What good is it making someone safer if it merely makes them miserable?" MM (An Adult)[2007]

The story of Manuela Sykes

- An older person with dementia, prone to falls and self-neglect
- Application by Westminster City Council to Court of Protection for deprivation of liberty to keep her in a nursing home
- Application opposed by Manuela and her nephew
- What is in her best interests? To return her home with a care package where she is at risk but happy, or to deprive her of her liberty so that she is safe?
- **How well do we support staff when faced with such a dilemma?**
- **Are we commissioning care and support packages to manage such situations?**
- **How accessible are specialists with expertise in law, mental capacity and safeguarding?**
- **See also Lancashire and South Cumbria NHS Foundation Trust and Lancashire County Council and AH [2023] EWCOP 1**

SAB governance – best practice

- SAB audits cases involving self-neglect and retains focus on obstacles to best practice
- SAB uses the evidence-base to hold partners accountable for practice standards
- SAB coordinates governance with Community Safety Partnership and Health and Wellbeing Board
- Workplace as well as workforce development
- SAB promotes procedures for working with self-neglect
- Use of SARs to inform practice and service improvement

Legal, policy and financial context

- Missing components in the legal rules
- Ongoing impact of financial austerity
- Government policies pulling against each other

The approach	What this might mean in practice
Building rapport	Taking time to get to know the person; refusing to be shocked; avoiding kneejerk responses; finding interests, history, stories
Finding the right tone	Being honest while also being non-judgemental, separating the person from the behaviour
Finding the right person	Working with or through someone who is well placed to get engagement
Going at the individual's pace	Moving slowly and not forcing things; continued involvement over time
Finding something that motivates the individual	Linking to interests or drivers for the self-neglect (eg waste/environment/recycling)
Agreeing a plan	Making clear what is going to happen; the next visit might be the initial plan
Starting with practicalities	Providing small practical help at the outset may help build trust
Bartering	Linking practical help to another element of agreement - bargaining
Focusing on what can be agreed	Finding something to be the basis of initial agreement, that can be built on later
Keeping company	Being available and spending time to build up trust
Being honest	Being honest about potential consequences

Factors to keep in mind during those early stages
What is the person's own view of the self-neglect?
Is the self-neglect important to the person in some way? Does it play a role as a coping mechanism?
Does the person have mental capacity in relation to specific decisions about self-care and/or acceptance of care and support?
Is the self-neglect intentional or not?
Is the self-neglect a recent change or a long-standing pattern?
Are there links between the self-neglect and health or disability?
Is alcohol consumption or substance misuse related to the self-neglect?
How might the person's life history, family or social relationships be interconnected with the self-neglect?
What strengths does the person have – what is he or she managing well and how might this be built on? What motivation for change does the person have?

Creative interventions

Theme	Examples
Being there	Maintaining contact; monitoring risk/capacity, waiting for the moment of motivation
Practical input	Household equipment, food hygiene, repairs, benefits, 'life management'
Risk limitation	Safe drinking, fire safety, repairs, adaptations
Heath concerns	Doctors' appointments, hospital admissions
Care and support	Small beginnings to build trust
Cleaning/clearing	Proportionate to risk, with agreement, 'being with', attention to what follows
Networks	Family/community, social connections, peer support
Therapeutic input	Replacing what is relinquished; psychotherapy/mental health services
Change of environment	Short term respite; a new start
Enforced action	Setting boundaries on risk to self & others

In summary: practitioner approaches

Practice with people who self-neglect is more effective where practitioners
Build rapport and trust, showing respect, empathy, persistence, and continuity
Seek to understand the meaning and significance of the self-neglect, taking account of the individual's life experience
Work patiently at the pace of the individual, but know when to make the most of moments of motivation to secure changes
Keep constantly in view the question of the individual's mental capacity to make self-care decisions
Communicate about risks and options with honesty and openness, particularly where coercive action is a possibility
Ensure that options for intervention are rooted in sound understanding of legal powers and duties
Think flexibly about how family members and community resources can contribute to interventions, building on relationships and networks
Work proactively to engage and co-ordinate agencies with specialist expertise to contribute towards shared goals

In summary: organisational approaches

Effective practice is best supported organisationally when
Strategic responsibility for self-neglect is clearly located within a shared interagency governance arrangement such as the SAB
Agencies share definitions and understandings of self-neglect
Interagency coordination and shared risk-management is facilitated by clear referral routes, communication and decision-making systems
Longer-term supportive, relationship-based involvement is accepted as a pattern of work
Training and supervision challenge and support practitioners to engage with the ethical challenges, legal options, skills and emotions involved in self-neglect practice

SAR findings

- Too accepting of "lifestyle choice & insufficient professional curiosity
- Mental capacity and risk assessments insufficiently robust
- Delays in raising safeguarding concerns or commencing Section42 enquiries
- Failure to escalate concerns to senior managers
- No agreed strategies to continue to engage
- Poor record keeping of decision-making

Hope – it is possible to align practice with the evidence-base

- Two case studies in a new article (Preston-Shoot, M., O'Donoghue, F. and Binding, J. (2022) *Hope springs: further learning on self-neglect from safeguarding adult reviews and practice.* Journal of Adult Protection, 24 (3/4), 161-178.
- So, what do we need to happen so that we can practise in this way?

Some references

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