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

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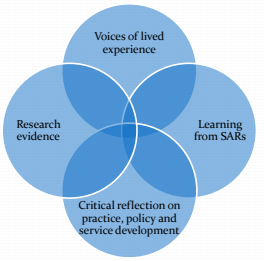
The Evidence-Base



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

- Learning from individual safeguarding adult reviews
- Analysis of 400+ 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 …

1. Understanding self-neglect: what do we know about prevalence?

- Scotland: 0.2% of the population (200 in 100,000)
- Ireland: 0.14% of the population (142 in 100,000)
- Australia: 0.1% of people over 65 (100 in 100,000)
- South Korea: 23%
- US: 29% of Chinese older adults; 22% of African-American older adults; 5% of white older adults
- UK: 20% of high-risk situations involving mental ill-health
- Hoarding: between 1.5%/6% of the population, pooled estimated prevalence of 2.5% (2,500 in 100,000)
- All ages, more common in older adults, severity increases
- Similar prevalence in men and women
- All socio-economic groups, more common in areas of deprivation
- Race: US - 58% white non-Hispanic, 20% Black/African-American, 18% Hispanic-Latino

Self-neglect and safeguarding

- US: 61% of referrals to adult protection services
- Ireland: 20/25% of elder abuse service referrals
- England: 4.2% of s.42 enquiries; 45% of SARs

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)).
- A poem about alcohol dependence that challenges the narrative of lifestyle choice. Periodically homeless, he died in temporary accommodation (in Adult Safeguarding and Homelessness: Experience-Informed Practice (2021) Local Government Association. www.local.gov.uk/publications/adult-safeguarding-and-homelessness-experience-informed-practice)
- 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."

Learning from the voices of lived experience

- Seeing the whole person in their situation
- Find the person
- 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, the notion of lifestyle choice is erroneous but too often an assumption or stereotype
- 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 multiple exclusion homelessness are in a "life threatening double bind, driven addictively to avoid suffering through ways that only deepen their suffering."

Keith's story

- Multiple influences on Keith's behaviour, and how they have affected his self-neglect journey
  - Focuses on how it felt for him, and what helped
  - His account helps us in understanding self-neglect
- https://www.youtube.com/watch?v=fhmfptpwNZc

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."
- *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 are homeless and any evidence of assumptions (unconscious bias) that someone may be undeserving; there are multiple reasons behind why a person may become homeless.
- *Assessment* – what does this individual need? Do not assume or stereotype.
- *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?

What people with lived experience says about how services work together

- *Collaboration* – widen the multi-agency, partnership and colocation approach; a breadth of expertise is needed to respond to individuals' complex needs involving physical and mental health, substance use and homelessness.
- *Safeguarding* – do not assume that people know what adult safeguarding actually is; for some it may be understood as the removal of children and as practitioners "working against, not with me."

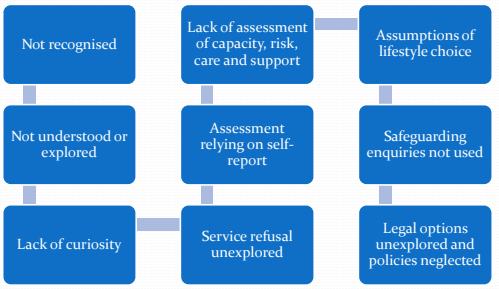
What people with lived experience advise organisations

- *Commissioning* – focus on evidence-based practice and what works. Hostels and night shelters are not suitable for everyone and can be more frightening than the streets. Wrap-around support is often crucial – "I would not have coped otherwise."
- *Managerial oversight* – understand the barriers to effective practice and learn from positive outcomes.
- *Supervision and staff support* – support a culture of reflective practice across teams to enhance practitioner wellbeing and resilience.
- *Service development with commissioners and providers* – use our expertise and experience to promote improvement and enhancement.

Comments from people with lived experience about governance

- *Review* – learn from failures.
- *Training* – education is essential so that practitioners and managers understand the multiple routes into homelessness and the pathways for prevention, intervention and recovery.
- *Involvement* – use our expertise.
- *Audit* – not just tick boxes but outcomes that matter to people.

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

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.

National guidance (NICE 2018)

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)

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

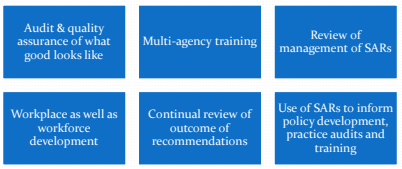
Inter-organisational environment – best practice

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



East Sussex SAB: Mr A

- Died July 2016, aged 64, no family contact
- Medical history: Korsakoff Syndrome, arteriovenous malformation, epilepsy, encephalopathy, type 2 diabetes, and bilateral leg cellulitis & ulceration
- Placed in nursing care in East Sussex Sept 2015, commissioned by West Kent CCG: no suitable local placement, placement opposed by Mr A and the LPA
- Placement (and DoL) in best interests as deemed to lack capacity to decide where to live
- LPA withdrew after the placement was made
- Self-neglect: refusal of care and treatment; practitioners uncertain what to do when acting in his best interests proved very challenging
- No adult safeguarding concerns referred until the final weekend; no multi-agency meeting with all services and practitioners present
- Cause of death: systemic sepsis, cutaneous & soft tissue infection of legs, diabetes mellitus, idiopathic hepatic cirrhosis

Using the voice of lived experience (SAR - Ms H and Ms I – Tower Hamlets SAB)

- In the context of people's experiences of multiple exclusion homelessness and 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 problem is a way of coping, however dysfunctional it may appear. Too often we are responding to symptoms and not causes. Put another way, individuals experiencing multiple exclusion homelessness are in a "life threatening double bind, driven addictively to avoid suffering through ways that only deepen their suffering."
  - 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.
- Making Safeguarding Personal is not just about respecting the wishes and feelings that an individual expresses.
  - He reflected on the challenge of knowing when to allow a person freedom of movement and when, for their own benefit, to curtail or supervise this. He described this as a "moral question." It is indeed a question that, in a multi-agency and multi-disciplinary forum, needs to be answered in each unique situation, drawing on an analysis of risks and mental capacity.

Salford SAB: Andy

- Andy died aged 32 at home.
- He required treatment for throat swelling, diabetes and renal failure; he did not always comply with his insulin regime or attend dialysis appointments.
- His living conditions in private rented accommodation were poor but his engagement with efforts to improve his housing situation was intermittent.
- He was living in poverty but his engagement with efforts to improve his financial situation was intermittent.
- He was known to self-neglect and to be hard to consistently engage. There was a pattern of rejecting assessments and treatment, followed by case closure.
- There are references to concerns about low mood and depression.
- Was he unwilling or unable to engage in the way services expected?
- There was some support/contact with a friend and family members but they were not consulted by the services involved.

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 and noted that Eric lacked mental capacity over a period of time but this was not picked up.
- Three years previously Eric had experienced a period of depression, anxiety and weight loss. More recently in August 2019 he had refused to eat and drink, and to take prescribed medication.
- His wife and daughter have described Eric as happy but a private family man. He perhaps struggled with getting older.

SAR Eric: Conclusions

- The influence of the lens through which cases are viewed
- 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

Isle of Wight – Howard (2018)

- Homeless single adult without local family support
- Impact of adverse life events
- Longstanding alcohol misuse (seen as lifestyle choice rather than impulse control disorder) 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; he declines support (undue influence on decision-making?)
- Refused housing as not regarded as in priority need
- No wet hostel available
- 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

Carol (2017) Teeswide SAB

- Attacked and murdered by two teenage girls
- Lack of understanding of coercive and controlling behaviour, of risk from others
- Long history of chronic alcohol use, mental health problems and vulnerability and had been identified as having multiple care and support needs
- Multiple agencies involved
- Diagnosed with a personality disorder - primarily Emotionally Unstable Borderline Personality Disorder (EUPD). Carol was therefore considered to have a dual diagnosis.
- Identified the need to develop existing treatments to better meet the needs of personality disordered substance abusers with therapeutic attention to reduce the severity of the substance abuse and other associated psychiatric problems such as depression, anxiety, paranoia
- Identified the need to consider executive functioning when assessing capacity

MS: City of London & Hackney SAB (2021)

- 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 and sleeping for several weeks.
- 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 is reported as having 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.
- When practitioners could not agree on whether he had capacity, they walked away, unable to reach a decision.
- Referred adult safeguarding concerns did not lead to a section 42 enquiry

Final Observations

- We have an evidence-base; we know what positive, good practice looks like.
- We need to focus on what facilitates and what blocks necessary change to "get to good" across the four domains of the evidence-base.

- How embedded is guidance, for example in supervision and decision-making?
- Emphasis on training but outcomes, if captured, variable and less emphasis on workplace development.

- No requirement to have local learning and service development strategies.
- Difficulty of obtaining SARs limits learning.

- Law seen as difficult to use; ethics difficult to navigate; few organisational spaces for reflection.

Some references

- **Preston-Shoot, M. (2018)** 'Learning from Safeguarding Adult Reviews on self-neglect: addressing the challenge of change.' *Journal of Adult Protection*, 20 (2), 78-92.
- **Preston-Shoot, M.** (2019) 'Self-neglect and safeguarding adult reviews: towards a model of understanding facilitators and barriers to best practice.' *Journal of Adult Protection*, 21 (4), 219-234.
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- **Preston-Shoot, M., Braye, S., Preston, O., Allen, K. and Spreadbury, K.** (2020) National SAR Analysis April 2017 – March 2019: Findings for Sector-Led Improvement. London: LGA/ADASS.

Comments & questions

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