What works? Best evidence for positive practice with people who self-neglect

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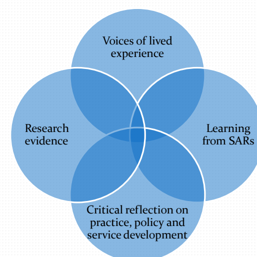
The Evidence-Base



The evidence-base from SARs for work with adults who self-neglect

- Learning from individual safeguarding adult reviews
- Analysis of 340+ 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

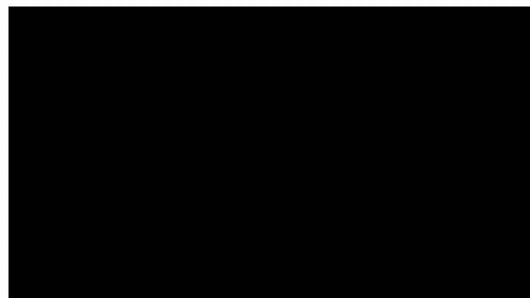
- When asked what he needed, Terence replied: “Some love, man. Family environment. Support.” He wanted to be part of something real, part of real society and not just “the system”. (reported in a thematic review on people who sleep rough, Worcestershire SAB (2020)).
- Adult N (Kirklees SAB) – a poem about alcohol dependence that challenges the narrative of lifestyle choice. Periodically homeless, he died in temporary accommodation.
- 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
- 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

- As you listen to the video:
  - Think about the multiple influences on Keith's behaviour, and how they have affected his self-neglect journey
  - Reflect on how it felt for him, and what helped
  - Consider how his account helps us in understanding self-neglect
- https://www.youtube.com/watc… Zc



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."

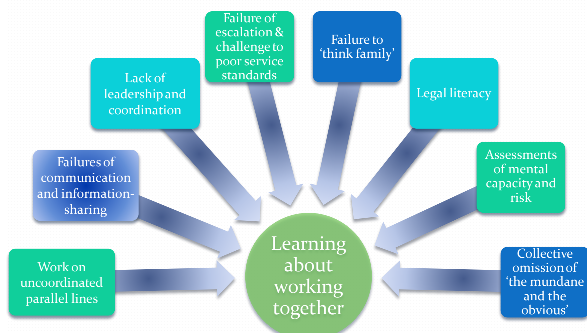
What people with lived experience advise organisations

- *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.

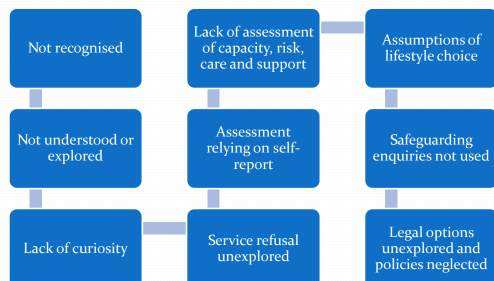
Comments from people with lived experience about governance

- *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.

Case reviews find shortcomings across the system

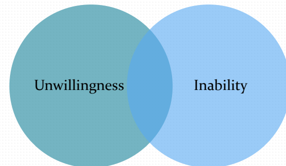


National Analysis Findings



Definitional complexity

- A wide range of manifestations (see the workbook for signs and symptoms)
- Arising from unwillingness or inability to care for oneself, or both
- Interlinked where unwillingness arises from the care and support needs of the individual
- Requires assumptions of 'lifestyle choice' to be questioned



Understanding the lived experience: neglect of self-care

- **Demotivation:** – self-image, negative cognitions
- **Different standards:** indifference to social appearance
- **Inability to self-care:** physical and practical challenges

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'm drinking, I'm not washing; I wouldn't say I'm losing the will to live, that's a bit strong, but I don't care, I just don't care.

"I wouldn't say I let my standards slip; I didn't have much standards to start with."

(It) makes me tired, very tired, and people who don't have it don't understand ... I get tired because daily routines are exhausting me, to do the simple things like get washed, put on clean clothes, wash my hair.

I always neglected my own feelings for instance, and I didn't address them, didn't look at them in fact, I thought 'no, no, my feelings don't come into it'.

Understanding the lived experience: neglect of environment

The only way I kept toys was hiding them.

I want things that belonged to people so that they have a connection to me.

Everything had a value to me ... everything in my eyes then and indeed now, has potential use

I don't have time to make a note of everything in the paper that has an interest to me and so I'm very fearful of throwing something away.

- **Influence of the past:** childhood, loss, abuse, bereavement
- **Positive value of hoarding:** emotional comfort, a sense of connection, utility
- **Beyond control:** voices, obsessions, physical ill-health, lack of space

The distress of not collecting is more than the distress of doing it.

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 …
- You don't see how things could be different
- You don't think you're worth anything different
- You didn't *choose* to live this way, but adapted gradually to circumstances
- Your mental ill-health makes self-motivation difficult
- You have impairment of executive brain function

Is it really protection when …
- Imposed solutions don't recognise the way you make sense of your behaviour
- Your 'sense of self' is removed along with the risks: "*hoarding is my mind*"
- You have no control and no ownership
- Your safety comes at the cost of making you miserable

A more nuanced ethical literacy

Respect for autonomy entails
- Questioning 'lifestyle choice'; respectful challenge; care-frontational questions
- Dialogue towards positive autonomy; maximise ability to see options and make care-ful choices

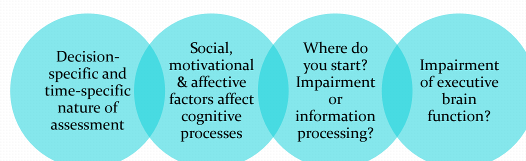
Protection does not mean
- Denial of wishes and feelings
- Removal of all risk

Autonomy does not mean abandonment
Protection entails proportionate risk reduction

Mental capacity: a reminder

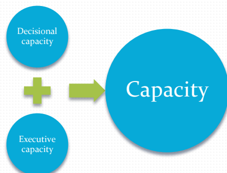
- Capacity is decision specific and time specific
- s.2, MCA 2005: A person lacks capacity if (at the time the specific decision has to be made):
  - They are unable to make the decision in question because of
  - An impairment of, or disturbance in the functioning of, the mind or brain
- s.3, MCA 2005: A person is unable to make a decision if they are unable to:
  - understand the information relevant to the decision, or
  - retain that information, or
  - use or weigh that information as part of the process of making the decision, or
  - communicate their decision

Challenges of mental capacity in self-neglect



- 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



Capacity

Putting this understanding into practice

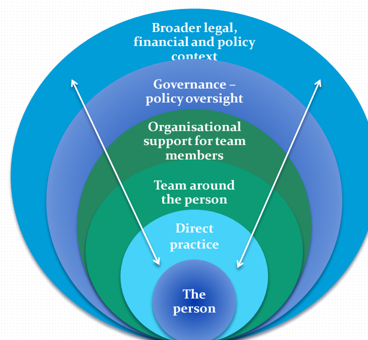
Decision-making difficulties may be masked by	Capacity assessment to take account
Articulate use of language; verbal reasoning skills; high perceived self-efficacy	Articulate and demonstrate models; the person in context; real world behaviour
Resulting in decision-making that is "good in theory, but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

National guidance (NICE 2018)

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)

Whole system understanding



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 – 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

But can we practise in this way?

- We have a strong evidence base from 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 – have a system wide conversation

East Sussex SAB: Mr A - a pen picture

- Died 24th July 2016, aged 64, Kent resident, 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 search ongoing, no suitable alternative
- Placement (and DoL) in best interests as deemed to lack capacity to decide where to live
- Supported in decision-making by a former colleague with LPA
- Self-neglect: refusal of care and treatment
- Cause of death: systemic sepsis, cutaneous & soft tissue infection of legs, diabetes mellitus, idiopathic hepatic cirrhosis

Mr A: Recommendations

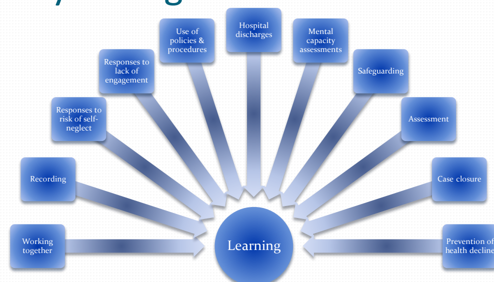
Using the voice of lived experience (SAR - Ms H and Ms I – Tower Hamlets SAB)

- In the context of people's experiences of multiple exclusion homelessness and self-neglect, the notion of lifestyle choice is erroneous.
- The problem is not the problem; it is the solution that is the problem. 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.

Andy: a pen picture

- 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.
- He lived alone. There was some support/contact with a friend and family members. There are references to “family dynamics.”

Key emergent themes



Milton Keynes – Adult B (2019)

- Adverse childhood experiences; substance misuse as response to trauma
- Unable to sustain hostel place due to substance misuse
- Unplanned hospital discharges
- Adult Social care assessments of his needs arising from autism and homelessness delayed and incomplete at time of death
- No lead agency or practitioner championing his unmet underlying needs
- Lifestyle and health concerns mount with no signs of professional scrutiny – no professional curiosity
- No mental capacity assessment or full safeguarding assessment
- No use of advocacy or escalation of concerns
- Lack of inter-agency response including multi-agency meetings
- Lack of management guidance, direction and supervision

Isle of Wight – 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
- 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 or modify existing treatments to better meet the special 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

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 in the London Borough of Hackney 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 Musa died.
- Referred adult safeguarding concerns did not lead to a section 42 enquiry

How? Why?

- Research pinpoints:
  - Client characteristics leading to neutralisation of moral concerns
  - Unconscious bias
  - Lack of wrap-around integrated provision to respond to trauma and adverse life experiences
  - Desensitisation
  - Complexity of work exacerbated by constraints
  - Policy overload, time and workload pressures
  - Complexity of legal mandates
  - Multi-agency working grafted onto single agency structures

Applying the Six Principles

- Empowerment – look beyond the presenting problem to the backstory; make every adult matter; listen, hear and acknowledge
- Prevention – commissioning to avoid revolving doors and to provide integrated wrap-around support; transitions as opportunities
- Protection – address risks of premature mortality
- Partnership – no wrong door; make every contact count
- Proportionality – minimise risk; judge the level of intervention required
- Accountability – get the governance right

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.

- Has the Care Act helped in England – inclusion of self-neglect, duty to cooperate, duty to review; but absence of power of entry & protection orders, impact of parallel processes and financial austerity, and limited requirements to publish findings?

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?

Summary of research findings: 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

Summary of research findings: 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

The last word…

- https://www.youtube.com/watch?v=ZEXrczADeKo&feature=youtu.be&medium=email&source=GovDelivery

Discussion

- How prominent are reviews in informing your day-to-day practice?
- How prominent is learning from reviews in informing your team's practice?
- How often might you and your colleagues discuss learning from reviews?
- How will you ensure that available guidance is used?

Journal articles

- **Braye, S., Orr, D. and Preston-Shoot, M. (2011)** 'Conceptualising and responding to self-neglect: challenges for adult safeguarding', *Journal of Adult Protection*, 13, 4, 182-193.
- **Braye, S., Orr, D. and Preston-Shoot, M. (2015)** 'Learning lessons about self-neglect? An analysis of serious case reviews', *Journal of Adult Protection*, 17, 1, 3-18.
- **Braye, S., Orr, D. and Preston-Shoot, M. (2015)** 'Serious case review findings on the challenges of self-neglect: indicators for good practice', *Journal of Adult Protection* (17, 2, 75-87).
- **Preston-Shoot, M. (2016)** 'Towards explanations for the findings of serious case reviews: understanding what happens in self-neglect work,' *Journal of Adult Protection*, 18(3), 131-148.
- **Preston-Shoot, M. (2017)** 'On Self-Neglect and Safeguarding Adult Reviews: Diminishing Returns or Adding Value?' *Journal of Adult Protection*, 19(2), 53-66.
- **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.
- Preston-Shoot, M. (2020) 'Safeguarding Adult Reviews: informing and enriching policy and practice on self-neglect.' *Journal of Adult Protection*, 22 (4) 199-215.
- 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.

Key contacts

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