Learning from reviews: human stories of adult safeguarding and self-neglect

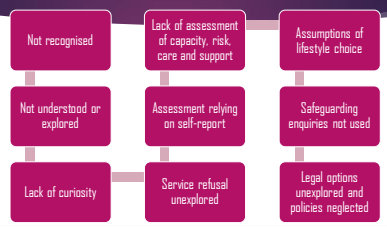
LEARNING LESSONS AND ACHIEVING CHANGE

HC-UK CONFERENCE – MARCH 2023

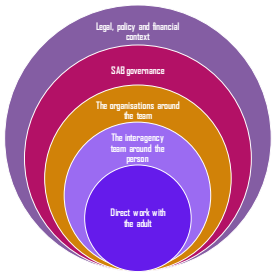
The evidence-base for working with adults who self-neglect

- Learning from individual safeguarding adult reviews
- Analysis of 500+ reviews in England
- Much smaller numbers in Wales and Scotland
- Research studies (SCIE, Journal of Adult Protection)
- SAR library (https://nationalnetwork.org.uk)
- 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

National Analysis Findings



The analytic framework: five domains



Helen's Message and Terence's Message

- "What hope do I have to ever recover or feel better when this keeps happening? I encourage anyone who truly care to come and spend a day with me to see what it's like to be helpless, when days feel like weeks, weeks feel like months." (reported in a Luton SAB SAR).
- 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)).

Extract of a Poem (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

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

- 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 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.

Wandsworth SAB – WWF (2017)

- A widow living alone with diagnosed multiple sclerosis. She holds strong views about the support she is prepared to accept but some care workers have developed very effective working relationships with her. Her deteriorating ability to mobilise and increasing difficulties with swallowing, transfers and hand movements has had a significant impact on her mood and ability to go out. It has become progressively difficult for her to smoke safely and there have been several small fires when she has dropped lighted matches or cigarettes, sustaining serious burns, aggravated by the emollient creams that are applied to treat skin problems. She refuses to stop smoking or to light cigarettes only when friends, family or care workers are present.
- findings – willingness to commission agencies with specific expertise; multi-agency communication; **challenge of balancing risk reduction approach with rights of adults with capacity to make choices; fire risk not part of risk assessment and management.**

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**.

Andy: a pen picture (2019) Salford SAB

- 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. BUT, **did services explore why?**
- 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.
- BUT, **was there sufficient curiosity and outreach?**
- He was known to self-neglect and to be hard to consistently engage. There was a pattern of rejecting assessments and treatment. BUT, was there sufficient outreach?
- There are references to concerns about low mood and depression. BUT, the initiative was left with Andy to engage.
- He lived alone. There was some support/contact with a friend and family members. There are references to "family dynamics." BUT, **services did not seek support from the family.**

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?

Direct practice – best practice

Person-centred, relationship-based	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

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**.

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.

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. **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 (2022)

- 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. This appears to have followed a relationship breakdown some five years previously.
- During this time he had experienced periods of homelessness, living in a car, in woodland or occasionally hotels. At times he was found living in insanitary conditions, self-neglecting, unresponsive and intoxicated. It appears that he had paid privately for detoxification and rehabilitation but this had not been successful.
- 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 ABE 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.**

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

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**

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

Thinking about change – a whole system conversation with SAB as the guiding presence

Legal, policy and financial context

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

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

Learning from Reviews (1)

- The need to improve
  - Safeguarding and legal literacy
  - Integrated whole system working
  - Recognition and assessment of care and support needs
- The need to clarify
  - Pathways into safeguarding
  - The role of different multi-agency panels
- The need to assess
  - The likelihood and significance of risks
  - Executive functioning after prolonged substance misuse
  - The impact of trauma and adverse experiences

Learning from Reviews (2)

- The need for creativity
  - Thinking collectively about ways forward
  - Avoidance of case dumping
  - Inter-agency mechanisms for responding to stuck and stalled cases
- The importance of wrap-around support
  - Not just for service users but also for staff: the work is challenging
  - The importance of time, relationships and being "held"
- The importance of candour and challenge
  - The importance of escalation of concerns
  - Ensuring all voices are listened to and included in multi-agency meetings

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 DOI. 10.1108/JAP-05-2022-0010.

Discussion

- What enablers and barriers do you encounter when working with people who self-neglect?
- How prominent are SARs in informing your day-to-day practice?
- How prominent is learning from SARs in informing your team's practice?
- How often might you and your colleagues discuss learning from SARs?

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.
- **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.** (2021) 'On (not) learning from self-neglect safeguarding adult reviews.' *Journal of Adult Protection*, 23 (4), 206-224.
- **Preston-Shoot, M., Braye, S., Preston, D., Allen, K. and Spreadbury, K.** (2020) National SAR Analysis April 2017 – March 2019: findings for Sector-Led Improvement. London: LGA/ADASS.

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