Self-Neglect and Safeguarding

Dr. David Orr

Huntingdon, Cambridgeshire
21st November 2023

NIHR

UNIVERSITY OF SUSSEX

What does the research tell us about:

- What is self-neglect and why does it happen?
- What do we know about how to engage with people experiencing self-neglect?
- How can we work together more effectively to support people experiencing self-neglect?

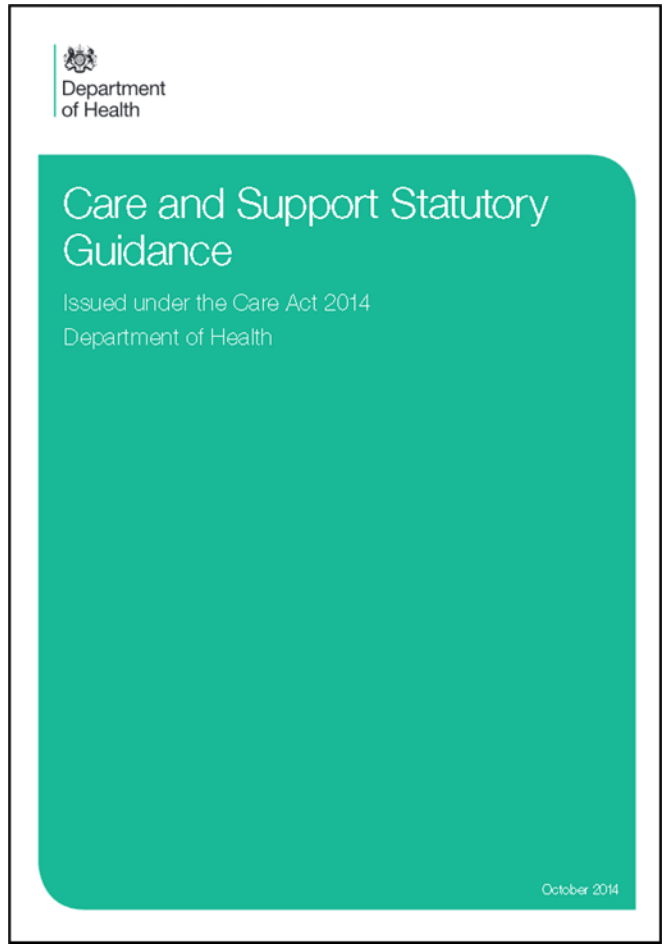
NIHR

UNIVERSITY OF SUSSEX

Self-neglect

- “covers a wide range of behaviour neglecting to care for one’s personal hygiene, health or surroundings and includes behaviour such as hoarding.”

  (Care and Support Statutory Guidance, s. 14.17)



How does self-neglect happen?

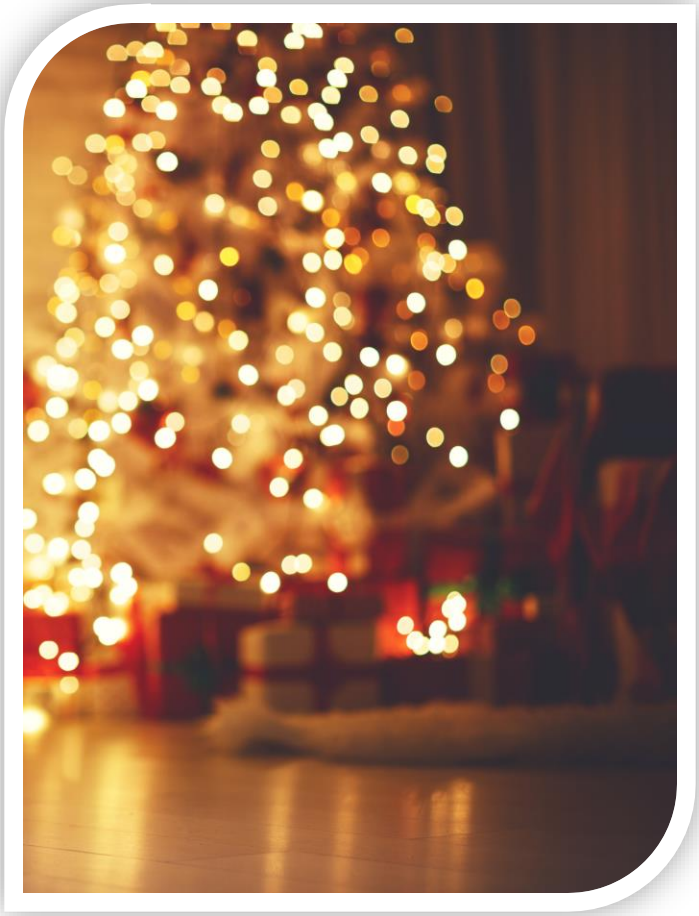
- *"I don't want anyone to help me, it felt on one hand, but on the other hand, I was dying to get out of bed. I was dying to get clean. I was dying to feel independent again. But I wanted to do it through my own force, my own strength. It was hard to ask for help after, you know, all those years that I went through […] and I didn't feel that I was helped or I, I, I had, I had the right to ask for help. And even then, I didn't have someone voluntarily ask me, […] you know, like straight away. I should have had all those helps."*

  "When you say neglect is to do with self and neglecting, but I don't see it that way. I see it both ways."

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

- *"I was still grieving that because nobody had ever really explored grief with me and enabled me to fully process the grief. And then it was grief about other things that had happened. Grief about not having any money, grief about not having any choices. And then grief of, well, if I'd had that help back then, maybe I'd be in a better position now."*

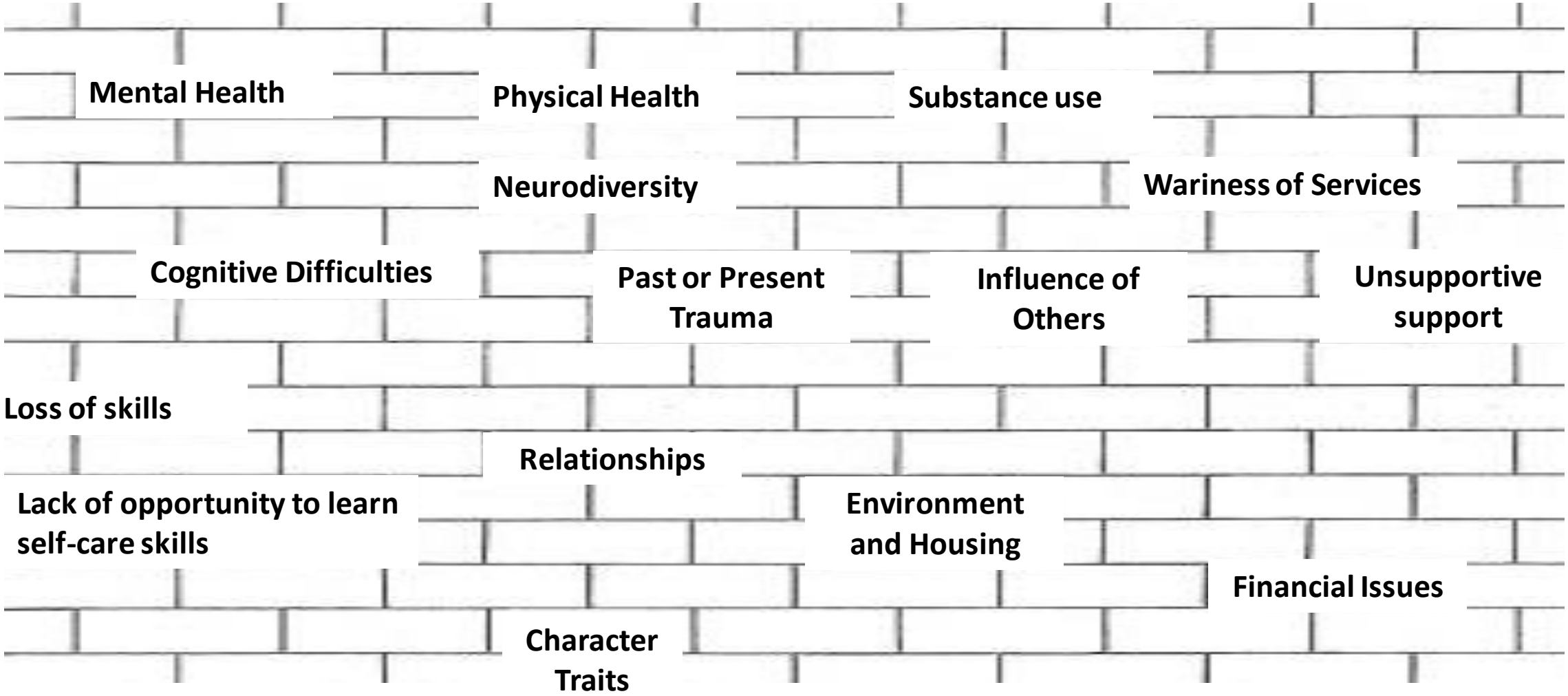
Living with Self-neglect



What do people have to say about what was behind their own experiences of self-neglect?

- **Demotivation:** hopelessness, health, loss, isolation, low self-worth
- **Different standards:** never cared much for social appearances, have other priorities, risk calculations
- **Inability:** mental distress, physical ill-health, homelessness, lack of space
- **Influence of the past:** childhood, loss, abuse, bereavement
- **Positive value (hoarding):** emotional comfort, connection to something, “my family”, hobby, to be appreciated by others

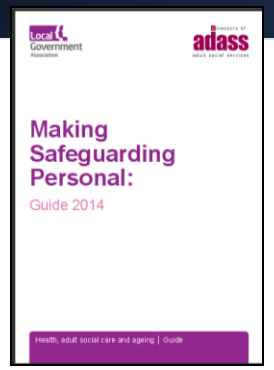
Self-neglect



… and how do they respond?

Refusal or withdrawal of permission for access	Avoidance or deflection of involvement	Permission for access and discussion, but outright rejection of support	Partial acceptance of input	Full acceptance of input

Making Safeguarding Trauma-Informed



- Empowerment
- Prevention
- Proportionality
- Protection
- Partnership
- Accountability

Safety

Trustworthiness

Choice

Collaboration

Empowerment

Cultural Consideration

Engaging people experiencing self-neglect: the dilemma

Engaging people experiencing self-neglect: What helps?

- Recognising openness to involvement, even if ambiguous
- A sense of timing
- Keeping the door open
- Honest recognition with service users of when they may have little or no choice in the matter
- Support that is responsive to person's own perception of their needs
- Working with service users to provide the right kind of input: not intrusive, encouraging, hands-on, person-centred, going the extra mile, reliable, compassionate, understanding

Engaging people experiencing self-neglect: Things to consider

- What is the focus – resolving behaviour or reducing harm?
- Going at whose pace? Not confrontation, but carefrontation
- Aspirations – identifying discrepancy
- Making connections through care for others

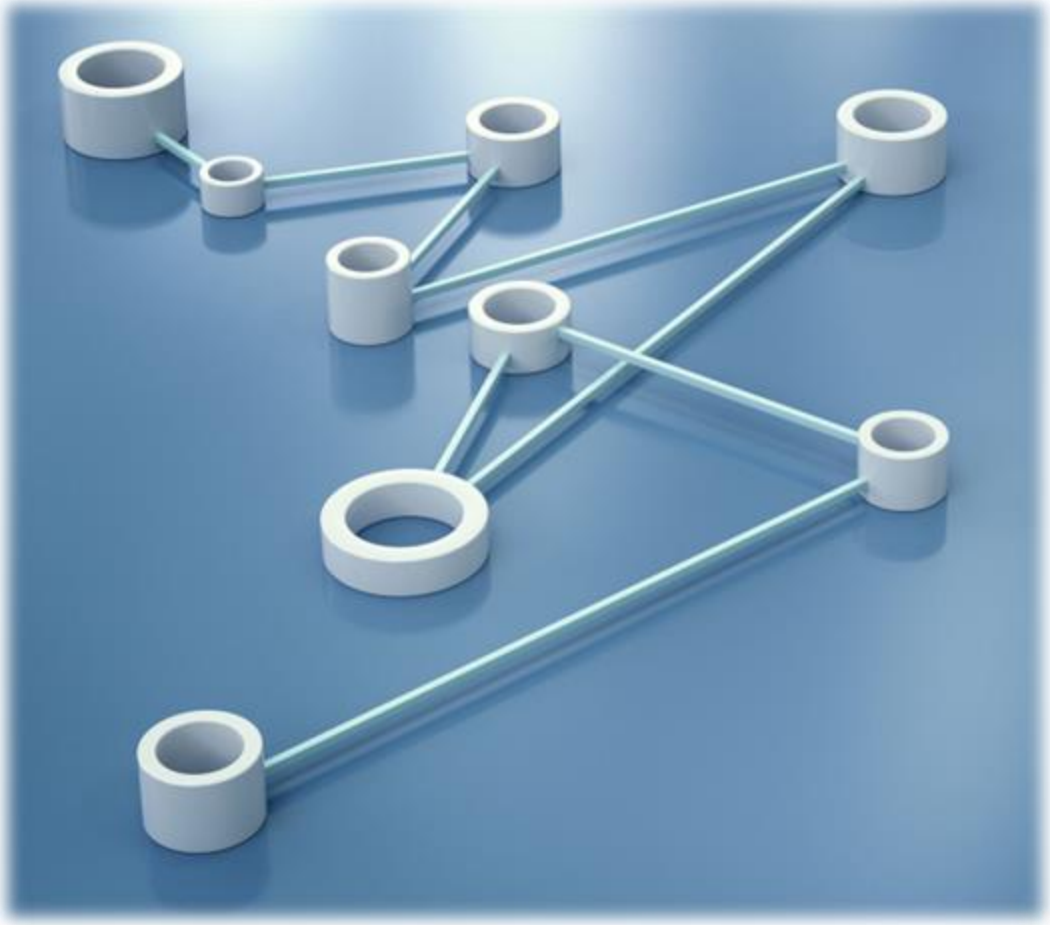
  "One service chipped away with a service user, reminding him of the effect he is having on other people. He is very empathetic and affected by the impact on other people, but he doesn't care about the effects on himself – it has got him through two years, when no-one thought he would."

Self-Neglect: Working Together

- Self-neglect is frequently complex, requiring multiple professional perspectives and close coordination.

but this presents challenges:

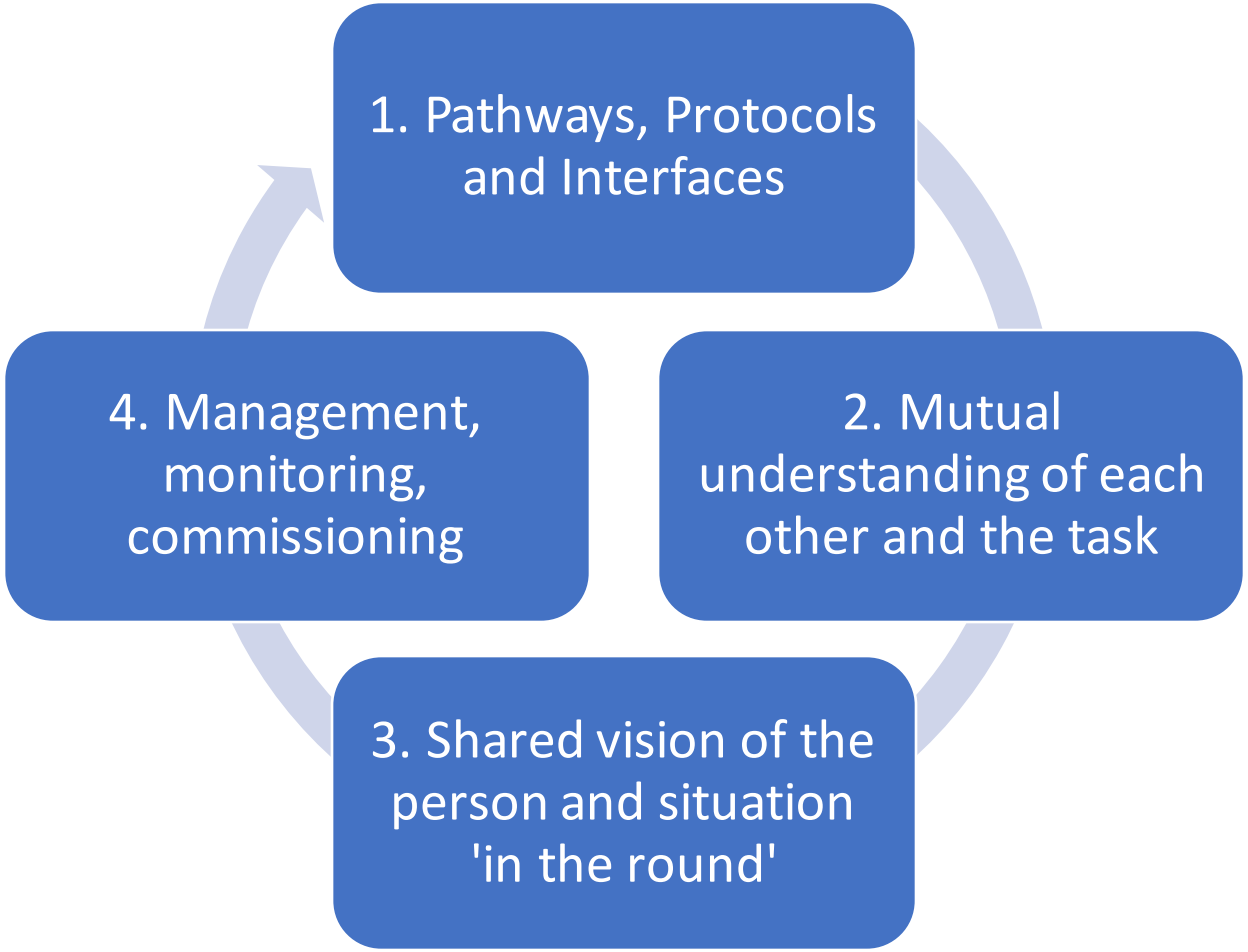
"I didn't know there was this whole team of people involved in 'fixing' my life until I later became part of a multi-disciplinary team as a professional. It made me wonder if maybe the team existed more to support each other, than to support me." (Taylor, Price & Clint, 2022, p. 45)



Self-Neglect: Inter-agency Working
(What do them over there think they're doing?)

- Poor role clarity
- Too much or too little 'ownership'
- 'Dead ends' for respectful professional challenge
- Uncertainty where to take cases
- Mental capacity not handled well
- 'Wrangling' rather than 'no wrong door'
- Multiprofessional perspectives: clashing not complementing
- Information not shared
- No feedback loop

Self-Neglect: Inter-agency Working
What is needed



Inter-agency Working: What is needed

1. Pathways and Protocols

- [ ] Referral pathways: who and when
- [ ] Protocols
- [ ] Procedures *and* relationships
- [ ] Feedback loops to build up knowledge and judgement

2. Mutual Understanding

- [ ] Adequate familiarity with each other's models
- [ ] Sensitised to each other's risk factors
- [ ] Shared language, levels of detail
- [ ] Coordinated activities under a shared plan

Inter-agency Working: What is needed

3. Shared Vision of the Person and Situation in the Round

- Shared efforts to understand – position of proportionate optimism
- Centring the person's perspective ahead of professional's or system's primary concerns
- Understanding people around the person – the right balance

4. Management, Monitoring and Commissioning

- Time, personnel, funds for self-neglect work
- Agreed mechanisms to share input
- Driving self-neglect work forward
- Actions in response to monitoring

What people who use services say they have valued

"Recognising self-neglect earlier I think is important. Once it's recognised earlier then, like I say, the idea is not to get too pushy about it; people start getting panicky then, you know? 'You're interfering in my life,' that kinda thing."

"She got it into my head that I am important, that I am on this earth for a reason."

"They all said, 'we're not here to condemn you, we're here to help you' and I couldn't believe it. I thought I was going to get an enormous bollocking."

"He's down to earth, he doesn't beat around the bush. If there is something wrong he will tell you. If he thinks you need to get this sorted, he will tell you."

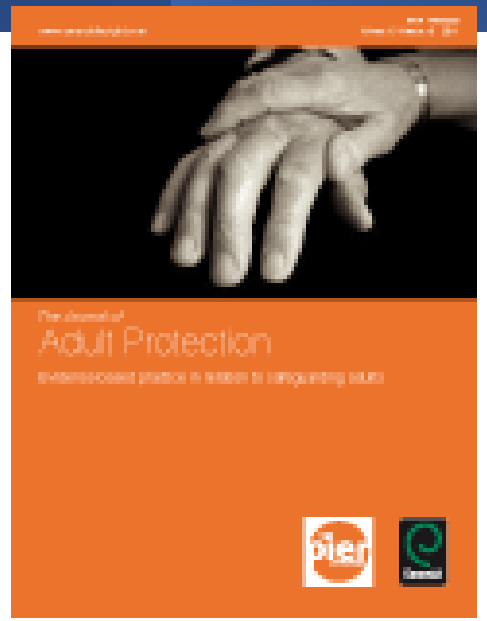
"Tenancy support started coming up but they weren't helping, they were just leaving it for me to do. Whereas when x and his colleagues came, they were sort of hands on: 'Bumph! We've got to do this' and 'Uh?!'""

"… He sees the needs … goes that extra mile."

Summary

- Time, persistence and ‘putting together the jigsaw’ may be needed to understand the roots of self-neglect
- How can services respond with awareness of trauma?
- Support =/= being Shanghaied; Autonomy =/= being adrift
- Working together effectively to support people experiencing self-neglect takes considerable skills – but if *we* find it complicated …

> “*I have come to believe that caring for myself is not self-indulgent. Caring for myself is an act of survival*.” – Lorde, A

Sources of Research Evidence

- Preston-Shoot, M: series of articles in Journal of Adult Protection analysing Safeguarding Adult Reviews featuring self-neglect
- Braye, S, Orr, D & Preston-Shoot, M (2014) Self-neglect policy and practice: building an evidence-base. Social Care Institute for Excellence. https://www.scie.org.uk/self-neglect/policy-practice/evidence-base
- Cornes, M et al. (2023) Opening the "too difficult box": strengthening adult safeguarding responses to homelessness and self-neglect
- Orr, D et al. (in preparation) Improving collaborative inter-agency systems and practice in self-neglect. https://njl-admin.nihr.ac.uk/document/download/2042088