Understanding and Responding to self-neglect among older people in England

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Introduction

We explored safeguarding and social care responses to self-neglect among older people to answer the question **'what works in practice?'**

NB just older people but also included hoarding

Long history of ‘doing something’ about self-neglect

- A sanitary or public health problem, also referred to as squalor and sometimes Diogenes Syndrome
- Removal under National Assistance Act 1948, section 47, as amended
- Very little used …

See BBC’s Call the Midwife, season 13

Definitions

Self-neglect: no established international definition

In England: Guidance to Care Act 2014 describes self-neglect as covering ‘a wide range of behaviour neglecting to care for one’s personal hygiene, health or surroundings and includes behaviour such as hoarding’ (Department of Health and Social Care, 2021)

Hoarding behaviour: two established definitions for **Hoarding disorder**

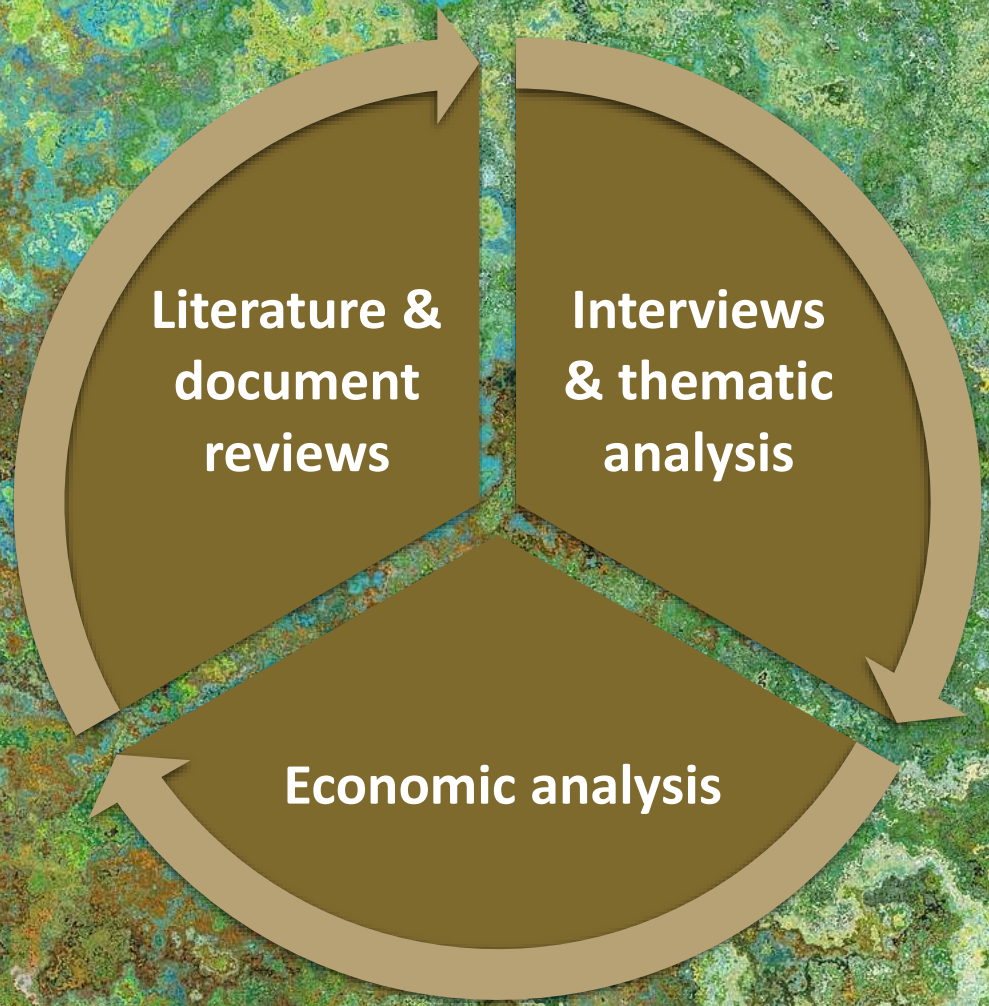
- Diagnostic and Statistical Manual of Mental Disorders: DSM-5 (American Psychiatric Association, 2013)
- International Classification of Diseases: ICD-11 (World Health Organization, 2018/2021)

‘Hoarding disorder is characterised by accumulation of possessions that results in living spaces becoming cluttered to the point that their use or safety is compromised. Accumulation occurs due to both repetitive urges or behaviours related to amassing items and difficulty discarding possessions due to a perceived need to save items and distress associated with discarding them.’ (ICD-11)

But of course in NI

Self-harm or self-neglect are not included within the definition of an 'adult in need of protection'. Each case will require a professional Health and Social Care (HSC) assessment to determine the appropriate response and consider if any underlying factors require a protection response.

Working with lived experience advisors, there were three parts of our study



We interviewed …

31 Safeguarding Adults leads and managers (+13 managers)

6 LA case study sites:

- 33 senior managers
- 60 frontline staff

8 older people with lived experience & 9 relatives or carers

Agencies and organisations interviewed:
Local Authority (LA) Adult Social Care, NHS Clinical Commissioning Groups, NHS Mental Health Trusts, GPs, Fire & Rescue Services, Police, LA Environmental Health, Housing Associations, LA Housing, Third/Voluntary Sector, and Professional Decluttering services

Economic analysis

Compared two scenarios based on Safeguarding Adults Reviews (SARs) involving three cases of self-neglect and/or hoarding behaviour.

- ‘Unmet needs’ scenario: SAR history of service use and professional involvement
- ‘Met needs’ scenario: use SAR to benchmark ‘what good looks like’ and modify history of service use and professionals’ involvement
- Economic implications on agencies’ budgets and costs over the last two years of life
- Unit cost data - based on literature and conversations with sector experts, study participants, and members of the advisory group
- To our knowledge, first attempt at economic analysis in this field

Findings

Findings

Definitions and perception of self-neglect

- Adult safeguarding leads and managers had varied understandings of the causes of self-neglect
- Frontline workers thought self-neglect arises from several possible causes: depression, anxiety, trauma, loneliness and isolation, schizophrenia, autism, and/or bereavement. (similar to perceived causes of hoarding)
- Care Act 2024 classification of self-neglect, including hoarding behaviour, as safeguarding concern was now well recognised by professionals
- Professionals and people with lived experience felt that some professionals considered self-neglect and/or hoarding behaviour as a choice

Findings

Referrals and assessments:

- Often a person came to the attention of statutory services (e.g. local authority - LA) when already at considerable risk of harm to themselves and/or others
- Safeguarding enquiry likely to be led by LA Adult Social Care
- Involvement of other agencies/organisations differed:
  - GP, Fire & Rescue Service, Community nurse, Environmental Health, NHS Mental Health, Housing, Friends, Family, Hospital, Neighbours, Police, Alcohol services, Advocate, Charities, Church – the individual
- General agreement to refer individual to LA Adult Social Care to assess if they needed care and support

Findings

Mental capacity or individual's ability to make a specific decision:

- Expectation that social workers, nurses or Occupational Therapists undertake mental capacity assessments in this area
- If person has decision-making capacity: potentially increased threshold for undertaking a safeguarding enquiry (investigation)
- If person found to lack specific decision-making capacity:
  - Potentially more safeguarding interventions
  - Few participants focused on empowering ethos of Mental Capacity Act

Findings

Support needed and challenges:

- Multi-agency responses help
- Long-term engagement rather than ‘quick interventions’ is preferable, building trust
- Missing knowledge of what other agencies/organisations are able/willing to provide
- Widespread criticism of lack of NHS mental health support
- Length of support could vary by:
  - Level of severity/risk
  - Consent and engagement of individual
  - Resources

Findings

Multi-agency working:

- Expectation that Adult Social Care would lead, but potential for agency ‘jealousy’ and ‘passing the buck’
- Mixed picture of shared understandings of definitions and thresholds
- At manager level good collaboration, but potential for ‘silo’ thinking/ working at frontline level due to high caseloads or lack of resources
- Third/voluntary sector not always fully integrated
- Information sharing, LAs and other agencies have policies and protocols in place
  - Questions around data/information sharing without consent

Findings

Training:

- Mixed picture on who had received training, across LAs and types of professionals, and whether it was thought helpful
- Higher proportion of frontline staff than senior managers had received training

- Main criticism: after training better knowledge of causes and consequences; but still largely unsure how best to support individuals
- Clear desire for more opportunities to talk through complex cases with colleagues

Findings

Economic analysis: overall findings (three SAR cases)

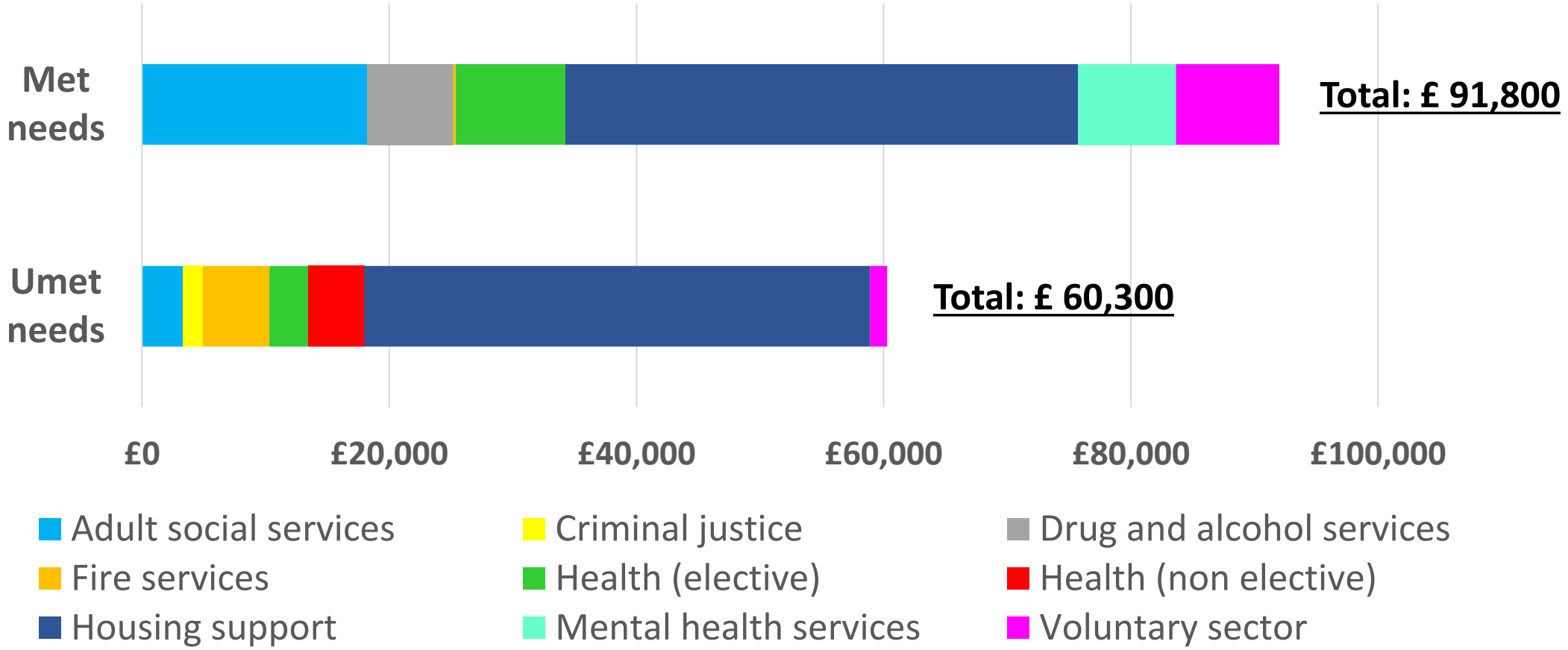
'Unmet needs' scenario:

- Expenditure on service provision in the last two years of life varied from £18,000 to £62,200 per person.
- Most of the costs were housing services (e.g., accommodation, maintenance/repairs, eviction, court action).
- Few resources from mental health services and drug and alcohol support.

'Met needs' scenario:

- Expenditure could vary from £68,500 to £85,000.
- Most of the funding would need to come from LA's care budget or housing services for home maintenance, homecare, and community support.
- About £2,100 per case for support from voluntary sector or community initiatives.

Example based on one SAR case: amount of resources (£) to be invested (over the last two years following SAR chronology) to keep people safe and to meet their needs:



Recommendations I

- Set up specialist multi-agency teams comprising professionals from at least social care/social work, mental health, housing, fire and rescue, environmental health, and voluntary community services. These teams need enough resources to allow engagement with individuals long-term, and to be able to follow-up and monitor.
- If no specialist team, multi-agency working can be improved by regular conversations about cases, increased participation by agencies, and better integration of third sector organisations.
- If external providers are commissioned, it is important that their services are based on a therapeutic approach, and that they can work with individuals long-term.
- Improving access to (community) mental health services for this group might be helpful. The implications of this would need to be explored further.

Recommendations II

- Assessments, especially Mental Capacity Act assessments, need to be undertaken with great sensitivity so as not to threaten individuals and discourage engagement with services.
- Some professionals still perceive self-neglect and/or hoarding behaviour as a choice. More awareness is needed of the influence of such beliefs, including in relation to making decisions.
- For frontline professionals, specialist training and supervision focussing on ways to directly treat and support may help improve outcomes long-term.
- Preventative approaches need to anticipate potential future needs. Anticipation may be possible at certain points in a person's life such as a bereavement or moving house, or through a shared multi-agency register flagging potential points of concern that should be monitored.
- There is some economic evidence that investing in services can improve outcomes for individuals and reduce the risk of harm - this could be taken into service planning.

Short quiz – for England's practitioners
LGA Making Safeguarding Personal

1. Self-neglect is usually a lifestyle choice. True or False?
2. Self-neglect doesn't always have to be the subject of a safeguarding enquiry. True or False?
3. If someone who is self-neglecting has mental capacity and refuses to engage in intervention, there is nothing that can be done to impose a solution. True or False?
4. Making safeguarding personal means you can only do what the person will allow you to do. We have to respect autonomy. True or False?
5. Making safeguarding personal takes too long – we don't have time, we need to find quick solutions. True or false?

Publications

NIHR | Policy Research Unit in Health and Social Care Workforce

KING'S College LONDON

Social care responses to self-neglect among older people: an evidence review of what works in practice

Stephen Martineau, Jill Manthorpe, John Woolham, Nicole Steils, Martin Stevens, Jennifer Owen, Michela Tinelli

NIHR Policy Research Unit in Health and Social Care Workforce
The Policy Institute, King's College London

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What do we know about hoarding behaviour and treatment approaches for older people? A thematic review

Nicole Steils, John Woolham, Jill Manthorpe, Stephen Martineau, Jennifer Owen, Martin Stevens, and Michela Tinelli

NIHR Policy Research Unit in Health and Social Care Workforce
The Policy Institute, King's College London

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Experiences of adult social work addressing self-neglect during the Covid-19 pandemic

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Abstract

• *Summary:* Internationally there has been much interes
19 pandemic on the care and support of older people inc
from self-neglect and/or hoarding. During the pandemic
duties remained to respond to concerns about harm ab
port needs living in the community. This paper reports i
working for adult safeguarding/adult protective services
recruited from all English regions. Interviews took
December 2020 as the pandemic's second UK wave wa
methods were used to develop themes.

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ORIGINAL ARTICLE

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Adult safeguarding managers' understandings of self-neglect and hoarding

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Abstract

Self-neglect and hoarding are behaviours that are hard to define, measure and address. They are more prevalent among older people because of bio-psycho-social factors, which may be exacerbated by advancing age. This paper aims to further understandings of self-neglect and hoarding in England's Care Act 2014 context, drawing on a study involving qualitative interviews with local authority adult safeguarding managers who play an important role in determining interventions with individuals who self-neglect and/or hoard. Online interviews were conducted with adult safeguarding leads and managers from 31 English local authorities in 2021. Interview data were subject to thematic analysis. This paper explores the commonalities and differences in adult safeguarding managers' understandings of the causes and consequences of self-neglect and/or hoarding among older people, which are likely to have tangible impacts on service provision in their local authority, and influencing of wider changes to policies and procedures. Most participants understood these phenomena as caused by a range of bio-psycho-social factors, including chronic physical conditions, bereavement, isolation. A minority took a more clinical or psycho-medical perspective, focusing on mental ill-health, or referred to the social construction of norms of cleanliness and tidiness.

Thank you

Further information and outputs are here:

https://www.kcl.ac.uk/research/self-neglect-and-hoarding-among-older-people

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