

NIHR School for Social Care
Research funded projects
at King's College London
2019-2024

NIHR | School for Social
Care Research
NIHR | Policy Research Unit
in Health and Social
Care Workforce



**Research into
social care with
very diverse
(& seldom heard)
groups**

About the NIHR School for Social Care Research and the NIHR Policy Research Unit in Health and Social Care Workforce at King's

The NIHR School for Social Care Research (SSCR) was established in 2009 and is one of the leading funders of research into adult social care practice in England. The Unit's work with SSCR was led from 2019-2023 by Professor Jill Manthorpe and from 2023-2024 by Dr Mary Baginsky.

Between May 2019 and early 2024, the Unit joined with six other partner institutions in a five-year phase of the School's work. Michelle Cornes, Jo Moriarty, Kritika Samsi, John Woolham, and Mary Baginsky were Senior Fellows of the NIHR SSCR.

Jess Harris, Stephen Martineau, Nicole Steils, Jennifer Owen, and Monica Leverton were Fellows of the School. Until his death in March 2022 Martin Stevens was also a Senior Fellow. Other Unit researchers working on SSCR studies included Tiffeny James, Caroline Green, Emily Thomas, Jo Brown and Cat Forward.

We thank all those who assisted with the research reported here – as participants, advisors and users of our study findings.

To find out more visit

www.kcl.ac.uk/hscwru/research/nihr-sscr-studies

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Research into social care with very diverse (seldom heard) groups 2019 - 2024

£2M funding from NIHR enabled many research related activities, including 17 research projects

Working with over



170
people with lived experience



850
practitioners

The NIHR SSCR was launched in February 2009 as a partnership between six leading research centres with excellence in social care research in England.

Its purpose was to carry out world-leading research in social care providing a focus for social care research within the NIHR and supporting the development of social care research more widely.

Researchers at King's College London undertook a wide range of projects using varied methods to focus on major social care challenges including those about workforce, carers, assessments and personalisation.

Projects employed a diverse range of methodologies:



Interviews



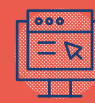
Thematic analysis



Economic analysis



Literature review



Website review



Focus groups



Co-production workshop



Go-alongs



Document review



Data synthesis



Meta analysis



Job-description analysis



Policy & scoping review



Narrative review



Communities of practice

In collaboration with



Expert Focus

Collaborative Safeguarding Hub



Working together with parents network

research in practice



Queen Mary University of London



Does Adult Safeguarding work for people experiencing homelessness and self-neglect?

J Harris, M Cornes, S Martineau, M Tinelli (LSE), S Burrridge (Expert Focus), B Ornelas (Collaborative Safeguarding Hub).

1st Oct 2019 – 31st March 2023



Methods



Interviews



Economic analysis



Communities of practice



Literature review

Project funding



£404,084

Findings

- Across England, adult safeguarding is not working coherently to address self-neglect where people are experiencing multiple exclusion homelessness (MEH). While there is good practice, there are also negative practitioner attitudes, service gaps and structural barriers that inhibit effective statutory responses.
- The specialist 'homelessness social work' role is potentially an important contribution to resolving this problem. It offers expertise in – and flexibility to work with – complex situations, to help address inequalities in access to statutory assessment, support and risk management.

- Negative experiences of services, stigma and discrimination contribute to high levels of service mistrust and deter people experiencing MEH from seeking or accepting help.
- Economic modelling found that shifting from limited, fragmented support (with repeated use of emergency services) to planned and timely multi-disciplinary support could lead to cost savings.

Implications for future

- Having expert practitioners – and lived experience – embedded within the study team, strengthens it throughout. Having a richly skilled (and committed) advisory group to advocate and shape the study strengthens it further, especially in generating impact.

Participants



30
people
with lived
experience



82
practitioners

Partners



Collaborative
Safeguarding Hub

Find out more



www.kcl.ac.uk/research/homelessness-and-self-neglect



www.youtube.com/watch?v=XRUX-FQbMJM

How does social care respond to self-neglect and hoarding behaviours among older people, and what works in practice?

N Steils, J Woolham, J Manthorpe, J Owen, S Martineau, M Tinelli (LSE), M Stevens & S Tynan (Age UK).

1st May 2020 – 31 July 2022



Methods



Interviews



Thematic analysis



Economic analysis



Literature review

Project funding



£391,634

Findings

- Self-neglect, including hoarding behaviour, may be a safeguarding concern. But professionals and people with lived experience reported that individuals' behaviour was seen as a choice by some. More awareness is needed.
- Supporting people who are self-neglecting and/or hoarding requires a multi-agency approach and clear agreements about who takes the lead in organising services and support. Different understandings of who takes responsibility can hinder better outcomes.
- Assessments need great sensitivity. Treatment and support often require long-term engagement, which enables trusting relationships.

Implications for future

- Great sensitivity is needed to build trustful relationships in the sector.
- Future research might explore the facilitators for and barriers to successful multi-agency working and safeguarding practice to address the complexity of needs associated with self-neglect and hoarding behaviours.
- The involvement of people with lived experience is critical to completing a successful study.

Participants



17
people
with lived
experience



137
practitioners

Partners



Find out more



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

How can the experiences of people who employed their own Personal Assistants during COVID-19 pandemic inform and improve care practice?

K Samsi, M Leverton, J Woolham & J Manthorpe.

1st October 2020 – 28 February 2022



Methods



Interviews

Project funding



£189,758

Findings

- Those who employed Personal Assistants (PA) faced difficult decisions around their support, often weighing up the risks of need for care versus the risk of catching COVID-19.
- Many employers felt alone in making difficult decisions, believing there was little attention to them – or to the PA workforce – in national government and local authority (LA) guidance.
- Some LAs did provide information for PA employers but this was often perceived as being slow, overcomplicated and non-specific.
- The pandemic brought to light that many PA employers lacked general understanding of employment law and their responsibilities.

Implications for future

- The COVID-19 pandemic elucidated and heightened the challenges that exist for people who employ social care PAs.
- The Direct Payment system was perceived by some as too rigid – and poorly aligned with notions of choice and control that are expected of it.
- Further research should be undertaken to understand:
 - how those who employ their own PAs come to a better understanding of employment law
 - what social workers perceive their role ought to be during emergencies.

Participants



70
people
with lived
experience

15
practitioners

Find out more



[www.kcl.ac.uk/
research/
employing-
personal-
assistants-
during-covid-19](http://www.kcl.ac.uk/research/employing-personal-assistants-during-covid-19)

How did 'COVID-19' easements to the Care Act 2014 operate?

M Baginsky, E Thomas, J Manthorpe & J Rapaport.

1st October 2020 – 31 March 2022



Methods



Interviews



Document review



Literature review

Project funding



£192,969

Findings

- The fact that easements were not used to any great extent suggests that they were not the response that adult social care needed.
- Local Authorities (LAs) that did use easements – as well as those that did not – both emphasised the importance of regional and professional groupings.
- Of those LAs that used easements, it was not clear that they had met the threshold to trigger their use. This was in part down to the difficulty of identifying a single threshold, as the guidance gave several different tests.
- It was difficult to determine the extent to which the decision to adopt easements was a preventative or financial one.

Implications for future

- During the pandemic, LAs had a vital perspective on what was needed to maintain the highest possible level of care, and their experiences must be used to contribute to future pandemic and emergency planning.
- Easements were developed by the government, yet when LAs used them they were subject to considerable opposition and even threatened with legal challenge. If such measures are sanctioned going forward – and used by LAs in accordance with guidance – the government should provide the necessary moral and public support to those who adopt them.

Participants



96
practitioners

Find out more



www.kcl.ac.uk/research/easements-to-the-care-act

How is mouth and teeth care addressed in social care assessments and care plans?

D Soilemezi (U of Portsmouth), K Wanyonyi (U of Cambridge), V Hill & J Manthorpe. 1st June 2021 – 31 January 2023



Methods



Interviews



Document review



Co-production workshop

Project funding



£88,882

Findings

- In contrast to the care home setting, few people working in homecare receive support and training about mouth and dental care – despite its importance to people living with dementia.
- Mouth and dental care are often not addressed in Care Act assessments and care plans, but get subsumed under ‘personal care’. Assessment documentation could usefully prompt inquiry into this subject.
- Social and homecare workers would like more training on mouth and dental care, particularly as it affects people living with dementia.

Implications for future

- In undertaking research on mouth and dental care it is very helpful to have dental expertise on the research team.
- Analysis of assessment documentation and care plans is possible and illuminating.
- Homecare workers who have developed skills in this area should be celebrated and listened to.

Participants



8
people
with lived
experience



38
practitioners

Partners



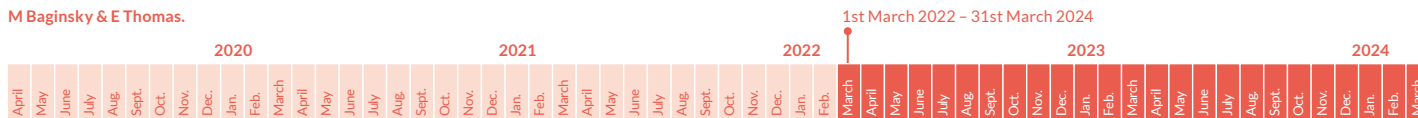
Find out more



onlinelibrary.wiley.com/doi/10.1002/gps.6032

What's the role of adult social care for parents with learning disabilities when a child is no longer in their care?

M Baginsky & E Thomas.



Methods



Interviews



Document review



Focus groups



Economic analysis



Narrative review

Project funding



£230,306

Findings

- Those working in adult social care (ASC) are often not aware of the key legislation that leads practice in children's social care (CSC), and vice versa. ASC and CSC practitioners both show low awareness of 'Good Practice Guidance on Working with Parents with a Learning Disability'.
- Working relationships between ASC and CSC were too heavily dependent on individuals and their own networks.
- Examples of ASC engaging with parents throughout the processes leading to the removal of children were unusual, but more common in authorities where there was an integrated learning disabilities team.

Implications for future

- Changes are needed to bring adult and children's services together including:
 - an assumption that there will be a holistic approach to dealing with adults and children within families.
 - a joint protocol across ASC and CSC, to be supported by a senior service liaison practitioner and a named person to lead from both.
 - joint training - including on early identification / screening tools.
 - pathways to support, developed by adult and children's services for parents at the point of removal.
 - representation of adult social care on Family Justice Boards.

Participants



9
people with lived experience



334
practitioners

Partners

Working together with parents network



Find out more

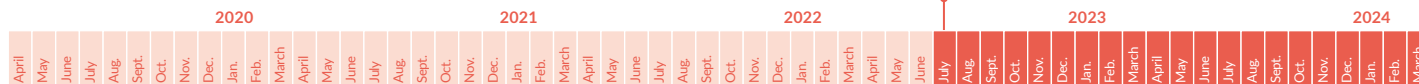


www.kcl.ac.uk/research/parents-with-learning-disabilities

How can we refine and evolve the role of 'Dementia Champions' in the homecare sector?

M Leverton, K Samsi, T James & C Newton.

July 2022 – March 2024



Methods



Interviews



Document review



Co-production workshop



Job description analysis

Project funding



£150,339

Findings

- Care staff should put themselves forward for the role of Dementia Champions, not be placed in the role by managers.
- In order to embed the role across the homecare sector, Dementia Champions need protected time to fulfil the requirements of the role.
- To maintain the role in the homecare sector, Dementia Champions must feel valued and supported by their employer.

Implications for future

- There is little longitudinal evidence available. More research is needed to evaluate the impact of Dementia Champions in the homecare sector.
- Working with homecare organisations from the start of a research idea is important to ensure successful recruitment and meaningful outputs.
- Thinking outside-the-box and using visual and interactive methods makes research accessible to people affected by dementia.

Participants



11
people
with lived
experience



67
practitioners

Find out more

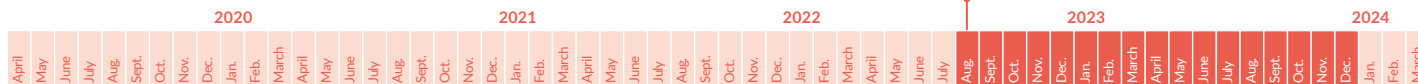


www.kcl.ac.uk/research/dementia-champions-in-homecare

What's the role of professional decluttering services in interventions with people who hoard, and who are known to adult social care?

J Owen, N Steils, M Brent, S Martineau, C Norrie & M Karnes.

1st August 2022 – 31 December 2023



Methods



Interviews



Go-alongs



Literature review



Website review

Project funding

£133,318

Findings

- The commissioning of professional decluttering services varies across (and within) local authorities, who do not require that declutterers have qualifications (or expected experience).
- Most professional declutterers do more than decluttering: most commonly cleaning, repairs, and helping with administrative tasks such as paperwork.
- People with hoarding behaviours who develop relationships with their professional declutterer trust them not to judge, not to push them to dispose of things, and to remove items to an agreed location.

Implications for future

- More research is needed on the experiences of people who receive decluttering help in combination with psychological support, such as CBT (cognitive behavioural therapy).
- There is growing understanding of the link between hoarding behaviours and ADHD. Interventions and training should be tailored with this in mind.
- Professional Decluttering is an example of an out-sourced service commissioned by LAs. Little is known about how external services like these are justified against policies, included in multi-agency approaches, and held accountable to appropriate standards.

Participants



6
people
with lived
experience



40
practitioners

Partners



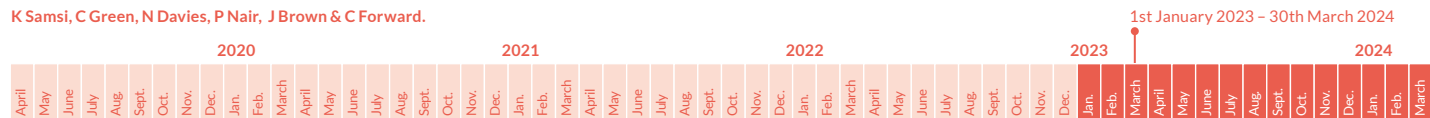
Find out more



www.kcl.ac.uk/research/decluttering

What worked well (and less well) with the 'Essential Caregiver' (ECG) role and what might have helped?

K Samsi, C Green, N Davies, P Nair, J Brown & C Forward.



Methods



Interviews



Co-production workshops

Project funding ³



£131,881

Findings

- COVID-19 lockdowns highlighted varied understanding, experiences, and implementation of the Essential Caregiver policy in health and care settings. It also highlighted the importance of the role of the care partner/supporter who wished to support their relative or friend.
- Participants were confused about the term 'care supporter', its definition, to whom it applies and the value of the title. 'Care supporter' was sometimes confused with roles like Next of Kin and Lasting Power of Attorney. Questions were raised in relation to expectations and responsibilities of the role, and the implications for people with no obvious person to take on the role.

- Clear communication is vital when defining the role, its boundaries, and how it applies in different settings (e.g. GP clinics, hospitals, care homes).
- Resources to support the role would help, as would clear guidelines from government, and good communication between the care supporter and health/care setting.

Implications for future

- As new policies on care partners in health and social care are implemented across health and care settings, further research is needed to investigate how these policies are accepted, understood and embedded into practice.

Participants



19
people
with lived
experience



35
practitioners

Partners



Find out more

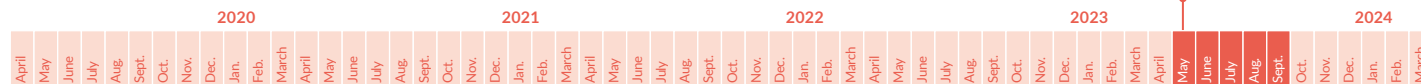


[www.kcl.ac.uk/
research/care-
supporter](http://www.kcl.ac.uk/research/care-supporter)

How do we better understand and improve training offers for professionals working with people with hoarding behaviours?

N Steils & J Owen.

1st May 2023 – 30 September 2023



Methods



Interviews



Thematic analysis



Literature review



Meta analysis



Data synthesis

Project funding

£14,504

12

Findings

- Most local authority-run training in this area, for agencies and organisations on adult safeguarding boards, focusses on raising awareness of hoarding behaviours, including the explanations of causes, risk factors, and how it affects people.
- Professionals need to receive more in-depth and multi-faceted training to feel equipped to work successfully with individuals with hoarding behaviours.
- Most practitioners expressed a need for access to clinical supervision or counselling services, to be able to reflect on and improve their work. Not all practitioners have such access.

Implications for future

- Access to high quality supervision for frontline professionals in local authorities and other agencies/organisations requires more attention.
- Involving people with lived experience in training programmes should be done sensitively to avoid sensationalising individuals' behaviour.
- Future research questions include examining the impact of decreasing budgets, not only for services themselves but also for training and development.

Participants



13
practitioners

Find out more



www.kcl.ac.uk/research/training-offers-for-professionals-working-with-people-with-hoarding-behaviours

Related short follow-on projects funded by SSCR

Evidencing the social work role within responses to multiple exclusion homelessness
(£8,073)

Examining mental capacity approaches to multiple exclusion homelessness
(£5,049)

Addressing multiple exclusion homelessness in social work education
(£13,199)

Dissemination of guidance on working relationships with adult social care for parents with learning disabilities when a child is no longer in their care
(£11,755)

Increasing the scope and involvement of key stakeholders and the impact of research into the essential caregiver role in primary and social care of people living with dementia.
(£7,850)

To find out more visit

www.kcl.ac.uk/hscwru/research/nih-sscr-studies

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