

Growing older, planning ahead: people with learning disabilities and carers

Submission date 20/07/2020	Recruitment status No longer recruiting	<input checked="" type="checkbox"/> Prospectively registered <input type="checkbox"/> Protocol
Registration date 28/07/2020	Overall study status Completed	<input type="checkbox"/> Statistical analysis plan <input checked="" type="checkbox"/> Results
Last Edited 02/09/2025	Condition category Mental and Behavioural Disorders	<input type="checkbox"/> Individual participant data

Plain English summary of protocol

Background and study aims

Of 900,000 learning disabled adults in England, two thirds live with family and one fifth are estimated to engage in behaviours that challenge. These behaviours often occur when someone is upset by change. Clear factors can generate distress for older learning disabled people including family carers growing frailer, early development of chronic conditions including dementia, and a lack of advance planning to avoid crises. Little is known about how family carers plan for their own end of life. A recent project, Embolden, focused on the experiences of older carers. A key theme was concern about the future. One dad, 72, said 'What keeps you awake at night is not knowing what the future holds for our son'. A mum, 92, said 'I just dread that day. What is going to happen? If they decide to uproot her I don't think she'll survive'. There has been little focus on how to address how services can best support older learning disabled people (aged 40+) and behaviours that challenge in later life. This study aims to improve support in this area by producing effective and workable recommendations and resources for future planning for older learning disabled people with behaviours that challenge, and end of life care planning for carers. The researchers will:

1. Review what is known about older learning disabled people with behaviours that challenge and family carers
2. Find out what support, resources and services exist for older learning disabled people with behaviours that challenge and family carers and identify examples of good practice
3. Explore how these two groups can be better supported by studying four examples of good support in England
4. Interview older family carers and learning disabled people about planning for the future and the end of life care plans for the carers, develop and evaluate resources to help people make decisions about this
5. Work with a range of people including older learning disabled people, family carers, self-advocacy groups, social workers, support workers, and people who provide, pay for and make sure services are good to produce workable recommendations to improve support for older learning disabled people and family carers.

The researchers will produce: recommendations for service providers and commissioners; decision aid tools and resources for older learning disabled people, family carers and support workers; two free courses for family carers and support workers hosted on the Open University OpenLearn platform; a continuing professional development course for social workers hosted by

the British Association of Social Workers; a support worker forum to share best practice hosted by the Open University; a film about the project findings and podcast about the research process on Socialcaretalk.org (sister site to Healthtalk.org); articles aimed academic and lay audiences. The researchers have a robust plan to make sure our project outputs reach the people they are aimed at. These include learning disabled people, family carers, self-advocacy and carer groups, social workers, support workers, service providers, commissioners and the wider public. The project team includes two learning disabled people and a family carer and learning disabled people and carers will be involved in the research.

Who can participate?

The research will involve all people who know about services for older people with learning disabilities and support for older family carers, for example NHS/social care commissioners, service providers and managers, clinicians, voluntary organisations and other professionals. It will also involve older people with learning disabilities (aged 40+), parent carers, siblings and the public.

What does the study involve?

The researchers would like to talk to senior leaders and commissioners in England of the NHS services for adult learning disabilities and end of life care, and adult social care; senior directors of the providers of supported living and residential care for older adults with learning disabilities including those whose behaviour challenges others and professional and public networks of those interested in this topic.

The research team will spend time with people and staff both within and outside selected care settings. They will conduct observations over several months, study documents and interview people with learning disabilities, family carers and staff.

The researchers will also conduct interviews and focus groups with older people with learning disabilities (aged 40+) living at home, elderly parental carers, and their sisters and brothers, to explore experiences, hopes and concerns about current and future living situations.

With a smaller sample of six parents and six people with learning disabilities the researchers will meet fortnightly for 6 months to work out solutions and develop a support programme. They will do this by, for example, creating a short film based on the interviews and discussions; watching this together with families, carers, people with learning disabilities and health/social care professionals; and working in small groups to identify activities and resources that will support how families prepare for parents' own end of life and the living options for their adult son or daughter. This will help them to develop resources to help with future planning and decisions ("decision-aids").

The researchers will work with ten family carers and their adult son/daughter with learning disabilities to test out the decision-aids as part of their own family decision-making. They will ask families to use diaries; researchers will observe meetings and take notes to see how the decision-aids are used and decisions are reached and they will interview them to find out more about their views.

What are the possible benefits and risks of participating?

This study will allow the researchers to think about how services for older people with learning disabilities can be improved and provide resources for people with learning disabilities, family carers, self-advocacy and carer groups, social workers, support workers, service providers, commissioners and the wider public. It is possible that people taking part in the study may feel some distress. The researchers are experienced in managing this.

Where is the study run from?

Manchester Metropolitan University (UK)

When is the study starting and how long is it expected to run for?
September 2020 to February 2023

Who is funding the study?
National Institute for Health Research (NIHR) (UK)

Who is the main contact?
Prof Sara Ryan, Sara.Ryan@mmu.ac.uk

Contact information

Type(s)
Principal investigator

Contact name
Prof Sara Ryan

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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

Integrated Research Application System (IRAS)
286973, 284854, 292248, 316474

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
NIHR129491

Study information

Scientific Title
Improving the support for older people with learning disabilities and behaviours that challenge others, family and professional carers, and end of life care planning for carers

Study objectives

To improve support for family (and professional) carers and older people with learning disabilities (aged 40+) with behaviours that challenge others by producing effective and workable recommendations and resources including end of life care planning for carers.

Ethics approval required

Old ethics approval format

Ethics approval(s)

1. Work package 2: Approved 14/07/2020, The Open University Human Research Ethics Committee (Human Research Ethics Committee - Research, Enterprise and Scholarship (RES), The Open University, Walton Hall, Milton Keynes, MK7 6AA, UK; +44 (0)1908 654849; research-rec-review@open.ac.uk), ref: HREC/3639
2. Work package 3: Approved 01/02/2021, London - Camden & Kings Cross Research Ethics Committee (no address; +44 (0)207 104 8086; camdenandkingscross.rec@hra.nhs.uk), ref: 21/LO/0062
3. Work package 4, Stage 1: Approved 13/11/2020, Social Care REC (no address; +44 (0)207 104 8070; socialcare.rec@hra.nhs.uk), ref: 20/IEC08/0035
4. Work package 4, Stage 2: Approved 09/08/2021, London - Camberwell St Giles Research Ethics Committee (no address; +44 (0)207 104 8138; camberwellstgiles.rec@hra.nhs.uk), ref: 20/IEC08/0035
5. Work package 4, Stage 3: Approved 25/07/2022, Yorkshire & The Humber - Bradford Leeds Research Ethics Committee (no address; +44 (0)207 972 2504; leedswest.rec@hra.nhs.uk), ref: 22/YH/0138

Study design

Work package 1: rapid scoping reviews
Work package 2: qualitative mapping exercise
Work package 3: qualitative observational study (service provision)
Work package 4: qualitative observational study (end of life care)
Work package 5: co-production of resources and dissemination

Primary study design

Observational

Study type(s)

Quality of life

Health condition(s) or problem(s) studied

Social care - people with learning disabilities and carers

Interventions

Current intervention as of 17/08/2022:

1. Three rapid scoping reviews focusing on older people with learning disabilities with behaviours that challenge and older carers
2. A scoping exercise involving interviews, documentary analysis with key NHS and local authority commissioners, providers and via social media to the wider learning disability community, to identify exemplar services for older people with learning disabilities that challenge
3. A 9-site ethnography of service exemplars involving observations, interviews and documentary analysis

4. Focus groups and interviews with older carers around end-of-life care planning, develop and test decision aid interventions using experience-based co-design methods
 5. Co-produce implementable recommendations for service improvement and innovative dissemination plans for the uptake of the project outputs
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Previous intervention:

1. Two rapid reviews focusing on older people with learning disabilities with behaviours that challenge and older carers
2. A scoping exercise involving interviews, documentary analysis with key NHS and local authority commissioners and providers, specialist third sector providers in England, and via social media to the wider learning disability community, to identify exemplar services for older people with learning disabilities and behaviours that challenge others
3. A 4-site ethnography of service exemplars involving observations, interviews and documentary analysis
4. Focus groups and interviews with older carers around end of life care planning, develop and test decision aid interventions using experience-based co-design methods
5. Co-produce implementable recommendations for service improvement and innovative dissemination plans for the uptake of the project outputs

Intervention Type

Other

Primary outcome(s)

Qualitative methods will be used:

1. To develop an understanding of existing evidence about the health (physical, mental and social) needs, service interventions and resources for family carers and older people with learning disabilities with a focus on those with behaviours that challenge in transition to greater supported care, including end of life care for carers (WP1).
2. Identify exemplars of good practice in services and support interventions in the UK for older people with learning disabilities, and their family and professional carers, with behaviours that challenge towards end of life (WP2).
3. To explore how older people with learning disabilities with behaviours that challenge and their carers can be better supported in later life by researching the commissioning and delivery of exemplar supported living services using ethnographic case studies (WP3).
4. To co-produce decision aid tools to support future planning and end of life care discussions for carers and future planning for older people with learning disabilities and evaluate their initial use (WP4).

Key secondary outcome(s)

Qualitative methods will be used to co-produce actionable recommendations for commissioners and providers, resources and decision-aids for carers and people with learning disabilities with behaviours that challenge, and online training materials about care in later life for social workers and professional carers (WP5).

Completion date

28/02/2023

Eligibility

Key inclusion criteria

Current inclusion criteria as of 17/08/2022:

WP2 MAPPING AND SCOPING EXERCISE - one of the following:

1. NHSE regional lead for learning disabled and/or the lead for end of life care
2. Key staff from Sustainability and Transformation Partnerships
3. Commissioner of services
4. Key staff from service providers
5. Key staff from relevant voluntary organisations
6. Public or professional with an interest in services for older learning disabled people and support for older carers

WP3 ETHNOGRAPHY

9 case study sites demonstrating exemplars in one of 4 models of provision (independent supported living, residential services, family-/home-based support and daytime activities and services, and Shared Lives). Per site:

1. 4-6 people with learning disabilities
2. 4-6 carers
3. 4-5 support workers
4. 1-2 commissioners, service managers, or other relevant staff

WP4

1. People with learning disabilities (aged 40+) who live at home with an elderly parent who have some verbal ability and who are able to give informed consent
 2. Parent carers with an adult child with learning disabilities (aged 40+) living in the family home
 3. Siblings of people with learning disabilities (aged 40+) who live with elderly parents
 4. Siblings (or close relatives) of people with learning disabilities who lived at home with at least 1 parent until the age of 35+, and whose home situation changed because either the parent(s) died or became too frail to care for them
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Previous inclusion criteria:

WP2 MAPPING AND SCOPING EXERCISE - one of the following:

1. NHSE regional lead for learning disabled and/or the lead for end of life care
2. Key staff from Sustainability and Transformation Partnerships
3. Commissioner of services
4. Key staff from service providers
5. Key staff from relevant voluntary organisations
6. Public or professional with an interest in services for older learning disabled people and support for older carers

WP3 ETHNOGRAPHY

4 case study sites. In each:

1. 5-10 people with learning disabilities aged 40+
2. 5-8 carers
3. 4-5 support workers
4. 1-2 relevant commissioners and service managers

WP4

1. People with learning disabilities (aged 40+) who live at home with an elderly parent who have some verbal ability and who are able to give informed consent
2. Parent carers with an adult child with learning disabilities (aged 40+) living in the family home
3. Siblings of people with learning disabilities (aged 40+) who live with elderly parents

4. Siblings of people with learning disabilities (aged 40+) who had to leave the parental home following parental death within the past 3 years

Participant type(s)

Mixed

Healthy volunteers allowed

No

Age group

Adult

Sex

All

Total final enrolment

256

Key exclusion criteria

Does not meet inclusion criteria

Date of first enrolment

01/09/2020

Date of final enrolment

30/09/2022

Locations

Countries of recruitment

United Kingdom

England

Study participating centre

University of Oxford, Nuffield Department of Primary Care Health Sciences

Radcliffe Observatory Quarter

Woodstock Road

Oxford

United Kingdom

OX2 6GG

Study participating centre

The Open University

Faculty of Wellbeing, Education and Language Studies

The Open University

Walton Hall

Milton Keynes
United Kingdom
MK7 1AA

Study participating centre

Manchester Metropolitan University

Faculty of Health, Psychology and Social Care
Manchester Metropolitan University
Brooks Building
53 Bonsall Street
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Study participating centre

Kingston and St. George's University

Centre for Health and Social Care Research
River House
53–57 High Street
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KT1 1LQ

Sponsor information

Organisation

Manchester Metropolitan University

Funder(s)

Funder type

Government

Funder Name

National Institute for Health Research

Alternative Name(s)

National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan

De-identified qualitative data will be available for 10 years post study completion to academic researchers with an affiliation to a research institution within the United Kingdom or another country within the EU for secondary analysis, provided consent for such use has been obtained from the participant and subject to approval by appropriate authorities at Manchester Metropolitan University or its collaborating institutions. Requests for data after the completion of the study should be submitted to Prof Sara Ryan, Principal Investigator (sara.ryan@mmu.ac.uk).

IPD sharing plan summary

Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article	Participant information sheet	01/06/2024	01/07/2024	Yes	No
HRA research summary			28/06/2023	No	No
HRA research summary			28/06/2023	No	No
HRA research summary			26/07/2023	No	No
Participant information sheet		11/11/2025	11/11/2025	No	Yes