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Growing Older, Planning Ahead

Plain English
Summary

June 2024

What is this summary about?

We are a group of researchers at different universities, people with learning disabilities and family carers.

We were given money from the National Institute of Health and Care Research to find out about the experiences of older people with learning disabilities and family carers.

The research started in September 2020 and finished in February 2023.

The full report of this research was published in June 2024.

This summary is a plain English summary of the full report. It has 9 chapters.

There are a lot of words because it was a very big project.

Chapter 1. Background

- We present information about what we know about older people with learning disabilities and family carers.
- We talk about the language we use in this report.
- We talk about what the research is about and why we did it.

Introduction

We do not know how many people with learning disabilities there are in England, the best guess is 1 million. We do not know how old those people are.

We know people with learning disabilities live longer than they used to.

We do not know much about the lives of older people with learning disabilities. We do not know how health changes or how the illness or death of family member affects people.

We do not know much about how family carers experience life as they grow older.

We know the least about people with learning disabilities without family.

The World Health Organisation says people should age well and be supported to live active lives, doing things important to them, in their communities.

Research suggests people live quiet empty lives with too much medicine.

People are at risk of depression, long term illness and dying early.

If people are not supported to plan ahead, things may go wrong when a family carer dies.

Changes can make people scared and sad and can lead to them being labelled as having **'behaviours** that challenge **others'.**

We do not know much about what good support is like for older family carers and older people with learning disabilities.

An organisation that funds research, the National Institute for Health and Care research asked:

How can families and carers be supported to provide care and support for people with learning disabilities and behaviour that challenges?

This research answers this question.
Learning disabilities and **'behaviours** that challenge **others'**

The language used to talk about learning disabilities has changed a lot.

Some people may not like having a label of learning disability. It can lead to people being treated badly.

We use the term **'behaviours** that challenge **others'** to show the challenge is with the person watching the behaviour.

'Behaviours that challenge **others'** are often a response to a difficult situation, previous trauma, illness or a lack of good support.

They may be a way someone is trying to calm down or communicate.

Even with good support **'behaviours** that challenge **others'** may remain.

Questions should be asked:
1) When and by who are behaviours considered challenging?
2) What can be done to adapt to **people's** behaviours, while keeping everyone safe?

The use of the term can be dangerous. Doctors may think people are not behaving well and miss illness symptoms.

This research focused on people over 40.

Background
Thinking about future planning
The small amount of research there is tells us people:

- are unhappy with services
- are worried about getting old
- are not offered support before a crisis occurs
- find their support networks get smaller as they age.

It also says:
- family carers and older people with learning disabilities help each other
- people feel overwhelmed and unable to help themselves
- some family carers make plans about the future
- carers from minority ethnic groups find it difficult to ask for help.

It is not clear who is responsible for starting to think about the future.

When planning was happening, it was not starting early enough.

The researchers found responsibility for caring for older people with learning disabilities did not always stop when people moved home.

A lot has been written, and promises made, about how people with learning disabilities can have good, independent lives in the UK.

This has not happened for many people. Family carers provide long-term care without support or confidence in alternatives.

In England in 2021/22, a third of adults with learning disabilities aged 18-64 lived with their families.

We do not know about those aged over 65.

Why did we do this research?
We wanted to know:
- how people can be supported to plan for older age
- how health and social care services can support older people with and without family
- how local authorities can meet the needs of this group.

Our research explored the health and support needs of older people with learning disabilities and family carers.

What did we ask and what was our aim?
What do people need to forward plan about future homes and end of life care for older carers?

What does good practice in services look like in the UK for older people with learning disabilities (and their carers), towards end of life? How are they delivered?

Aim
To improve support for family carers, older people with learning disabilities (aged 40+) by producing effective recommendations and resources to support planning ahead for a good older age.

Chapter 2. What we know about the needs and experiences of older people labelled with 'behaviour that challenges others' and their family carers

- We looked at what was written in research, policy and practice.

- Review 1 looked at what is written about older people with learning disabilities and 'behaviours that challenge others'.

- Review 2 looked at what is written about family carers of older people and 'behaviours that challenge others'.

- Review 3 looked at what is written about how care is arranged for older people and 'behaviours that challenge others'.

- We found there is not enough good support or information available. More research is needed to understand how things can be improved.

Introduction
We do not know much about how older people with learning disabilities, and their family carers, experience moving out of their family home.

We looked at what was written from research, policy and practice guidance. We wrote reviews summarising what we found.

What we wanted to know
To understand the health needs, services and resources for older people with learning disabilities labelled with 'behaviour that challenge others', and family carers.

What we did
We used a method called 'systematic rapid scoping review' to understand what was known as broadly as possible.

We collected evidence from lots of places and reviewed it.

We followed guidance about what to include in the review. We had help from our public and professional advisory groups.

What evidence was examined
We looked at different types of information.

We included research reports and articles, guidance for policy makers and people working in social care.

We did not include writing where people gave their opinions on research.

We included studies that collected new information and looked at what previous research had found.

Definitions and who was included
Older people with learning disabilities were 40 or older. Family carers included parents and siblings. Care referred to people living anywhere within the community.

When looking at **'behaviours** that challenge **others'** we used more words to find evidence. These included **'challenging behaviour'** and **'behaviours** of **concern'.**

Where information was found
We had help from a librarian. We looked at databases where research is listed and stored. We searched each one with the same key words.

Deciding on which evidence to include
We looked at the information on our own, deciding if it should be included.

We shared our answers with the team and discussed if we disagreed.

We then made a list of documents to read. For each review one researcher read it all and decided if it should be included.

Review 1 included 9 papers, Review 2 had 7 papers and Review 3 had 9 papers.

We searched back to 2001 for Reviews 1 and 2. There was no time limit for Review 3.

Pulling the findings together
We read the evidence we decided to include and sorted it into categories.

We found patterns in each review, relating to the questions we had asked.

We wanted to explore and understand the evidence, not just describe it. We wanted to create new ideas about the information we found.

What we found
Review 1: Health and social care needs for older people with learning disabilities and those labelled with **'behaviours** *that challenge* **others'** *moving home*

The review suggested:
- ageing family carers, and people with learning disabilities, do not plan for moves
- professionals should support families before problems occur

- Commissioners who buy services should plan and ensure there is housing and support for people.

Review 2: Health and social care needs of family carers of older people with learning disabilities and those labelled with **'behaviours** *that challenge* **others'** *moving home*

The review suggested:

- advice, information and support to help families plan was not easy to find and use

- suitable housing and support were not always available

- few resources are designed to help people plan ahead.

Review 3: How care can best be coordinated for older people with learning disabilities and those labelled with **'behaviours** *that challenge* **others'**

The review found three parts to organising care well:

- individual level: requires good communication, thinking about difficulties of ageing, delivered by skilled staff

- service level: requires teams and services to work together, including those in housing, and those with expertise in learning disability

- local/regional level: requires those buying services to look at current and future needs.

What it means

The reviews showed the term **'behaviours** that challenge **others'** is of limited use. How people work together and understand each other can help or hinder people when they move home.

There is little evidence about successful moves for older people. What there is suggests supportive and consistent staff are key.

We found gaps in the support for older people and family carers.

There were no resources or guidance to help older people to plan.
Support should be provided before a crisis happens. Older people living with family may need support to build confidence to live elsewhere.
Consistent support from a known social worker can help people and family carers.

Older people should have easy access to good healthcare to help identify ill-health which might lead to the label of **'behaviours** that challenge **others'.**

Little evidence exists about the support needs of family carers.

Be careful

We may have missed some evidence due to the search terms used.

We found little evidence about older people with learning disabilities labelled with '**behaviours** that challenge **others**' moving home.

We relied on evidence about moving home or about younger people labelled with '**behaviours** that challenge **others**' moving home.

Most evidence was 10 years old and may be less relevant today.

So what?

The reviews show the needs of older people, and their family carers should be important in health and social care.

People who decide on policies or what services should be available should be more proactive in supporting people as they age.

Older people and family carers should be involved in planning and decisions about the future.

Decisions should consider **people's** whole lives, their friendships and family, their homes, and activities, not just health or social care needs.

Careful planning is needed for older people labelled with '**behaviours** that challenge **others**' to live in their own homes.

Chapter 3. Identifying good examples of older people with learning disabilities, labelled with 'behaviours that challenge others' living in their community

- We looked at how people describe excellent support for older people with learning disabilities.

- We looked at what was written by organisations for people with learning disabilities and by those who decide what services should be provided in England.

- We found four key types of support.

- We found some places people thought were good.

Introduction
We do not know what good practice looks like for older people with learning disabilities labelled with 'behaviours that challenge others'.

We do not know what helps people live in their community.

The support people receive may be called different things, but includes support to:
- wash and dress, cook, clean and shop
- have a job
- take part in community activities
- visit the doctor

Support may be provided to one person or shared among a group of people who live together.

What we wanted to do
Find examples of good practice in the UK for older people with learning disabilities.

Draw up a shortlist of good services to contact and go and hang out in.

What we did
We could not find a list of what good looks like so we made one.

Creating criteria for what good looks like
We grouped the information we collected into categories to help decide what good services look like.

We had help from the project advisory groups and other people interested in the research.

We spoke to people in 30 services and received 9 responses to an online questionnaire.

We looked at information, comparing it to the categories we had drawn up.

When we grouped things differently, we had a discussion before making a shared decision of whether to include something.

This resulted in a larger set of categories of what good looked like. These were discussed by the project advisory groups.

Identifying good services
We looked at existing services and compared them to our list of what good looks like.

We took two approaches to finding services:

- we talked to people who work for NHS England or local authorities whose job it is to ensure services exist
- we talked to people who provide services.

Someone who works for the regulator, the Care Quality Commission, helped us search their records of care providers.

We read all the information we collected and used it to decide whether services were examples of good practice.

What we found
The full list of what good looks like is at the end of this report. It includes people choosing who they live with and having daily plans and activities.

The search of CQC records found four potential providers, who ran 74 services.

We also collected suggested examples of good practice from speaking to other people.

All information collected was compared to the criteria. 15 services were identified to use in the next part of the research.

What it means
We identified four models of community support for older people with learning disabilities labelled with **'behaviours** that challenge **others'.**

People were living:

- in their family home with family carers, who may receive support funded by the local authority
- in their own home in Supported Living services. They may own their home, hold a tenancy agreement and rent it, or be provided with a personalised care package that includes accommodation
- in Shared Lives, with paid care provided by a family in their family home
- in residential homes, with or without nursing care.

All these options were included in the short list of services identified.

Chapter 4. Spending time hanging out with people to find out about their lives: Ethnography

- We talk about an approach called ethnography. This means hanging out with people to find out about their lives.

- Researchers spent time with people in their homes.

- They interviewed people with learning disabilities, family carers, support workers, managers and local authority staff.

- They read and thought about the paperwork organisations had to help staff do a good job.

Introduction

Researchers cannot rely on what people say is good practice, without checking for themselves.

To do this we used an approach called ethnography. That involves hanging out with people, watching and taking part in what happens to them.

Researchers from universities and with lived experience (people with learning disabilities and family carers) worked together. They had online meetings in between visits to discuss things.

What we wanted to know

What good looks like in **people's** lives.

What we did

Researchers spent time in nine places where people live (found to be good earlier in the project).

Choosing where to visit
Eight places were approached to take part.

One more place was included. It was a new service for older people with learning disabilities and complex needs in a city. It was not yet open, so it was looked at differently to the other places.

Model of care	Number of sites	Time spent in them
Independent supported living	4	20 days
Residential nursing home	2	20 days

Live with family, use day activities	1	20 days
Shared Lives	2	20 days

Arranging to do the research
We spoke to people who ran the organisations and asked if they would like to take part.

We talked with staff to explain why the research was important, and why they might like to take part.

We spoke with people with learning disabilities to check that they were happy to take part.

If people were not able to say if they were happy their relatives were spoken to.

Some organisations had staff shortages and joined the research late or took a break from the study.

One organisation chose not to take part. They felt unable to offer excellent support, due to COVID. Another organisation was approached to take their place.

Researchers talked with the people living and working in the organisations they visited. They were all white British and aged 40-70. People lived in the countryside, small towns and cities.

Preparing the research team
Resources were developed to train the team. People had key skills including watching and listening to people. The resources explained how these were useful for research.

The resources are here https://www.mmu.ac.uk/research/research-centres/hpac/projects/growing-older-planning-ahead.

How the research team worked together
University researchers and researchers with lived experience visited sites together 30% of the time.

The research team talked about what they had seen at the end of a visit, and the university researcher took notes.
If this was not possible, they talked online or by phone later.

Three online meetings were held for the team to discuss the visits.

Life insights from researchers with lived experience
Researchers with lived experience bought important knowledge.

One researcher who used a wheelchair commented on the lives and homes of two participants who used wheelchairs.

Others used experiences of being CQC Quality Checkers to think about the research.

Researchers with lived experience who lived locally to sites brought knowledge of local places and self-advocacy groups.

Getting permission from people to take part
People were given information about the research and asked if they would like to take part.

Easy Read information sheets and consent forms were used.

Researchers went through the forms with people, and with someone supporting them if they wished and answered any questions.

People were told they could stop taking part in the research at any point.

What information was collected
The research team visited places where people lived, spent time with them, and looked at paperwork.

We wanted to understand how people were supported in their daily lives, how they aged, and how **'behaviours** that challenge **others'** were understood.

Researchers spent between 12 and 25 days, including weekends and evenings, visiting people in each type of care.

They kept detailed notes about what they saw.

Researchers interviewed people with learning disabilities, family members, support workers, managers and local authority staff who paid for the service.

The interviews were recorded, and notes were made from the recording of what people said.

People with learning disabilities – interviewed and hung out with	13
People with learning disabilities – hung out with, no interview	24
Interviews with family members and carers	17
Interviews with support workers and local staff	26
Interviews with those buying the service and service managers	15
Total	95

Documents and paperwork
Policy documents, that say how things should work, were requested from each site visited.

These show how the organisation should support people with learning disabilities labelled with 'behaviours that challenge others'

These show what support should be given around growing older and end of life care.

Documents about restraint and mental capacity were collected.

If there was no policy on end-of-life care, documents about health and wellbeing were looked at.

What we did with the information collected

Information collected (notes, interview transcripts, and policy documents) was read and categorised to find similar things from across the sites about people's lives.

We were interested in small details about people's lives in their local community.

We held two workshops for researchers with lived experiences to contribute to the analysis.

These workshops looked at parts of the information where people talked about 'behaviours that challenge others'.

The site in development

When the research began a new nursing home in a city was suggested to be part of the research.

It was still not open when the research started.

Researchers and Advisory Groups agreed to keep the site in the study.

We wanted to learn from the process of planning a new service for older people with learning disabilities.

The proposed site

The service is a large residential home with nursing, for up to 70 people.

Ten beds are reserved for a "household" for older people with learning disabilities and complex physical and mental health needs.

The home is in a community, on the site of an older people's care home.

Plans include a community café to support community engagement.

What information was collected
We collected documents about the development.

We interviewed the project manager, the commissioner who is responsible for buying services in the site, a local councillor and the chair of a parent carer group.

We attended the 'co-design **group'** meetings for the 10-bed household.

Information was collected about the number of people with learning disabilities currently receiving support from the local authority.

What we did with the information
The information was read, re-read and put into an order to find learning from the process.

The research team talked about the findings to better understand them.

Chapter 5. What we found from hanging out with people where they lived

- We found out about the **person's** home and where it is, how support is organised and how people are supported to have a social life.

- We saw examples of good support that helped people lead happy and healthy lives as they got older. This included making sure people were supported by staff they liked and knew well.

- We were surprised to find some people had little choice about where they lived, who they lived with, who supported them, and how they spent their time.

- We found most services and staff were not thinking about how to support people as they grow older.

- We found '**behaviours** that challenge **others'** lessened or stopped when people got good support.

Where people live

Where someone lives, and what it is like, is important.

It is important the house, flat or room is accessible, and can change to meet their needs as they grow older.

Where someone lives should feel like home. It should be safe and secure. It should be there forever, and it should be personal to them.

Homely homes
People who lived on their own with good support reported feeling house proud and happy in Supported Living.

People living in Shared Lives homes were in comfortable and welcoming family homes.

People in a nursing care home were supported to make spaces that reflected them, including in shared areas.

Access to the outdoors
Some people had gardens with plants, bird feeders and seating areas.

People were encouraged to grow plants and vegetables in their gardens.
One person lived on a small farm with their Shared Lives carers. He loves working with his animals and spends most of his time outside.

*Where **people's** homes are.*
Being able to walk or travel around the neighbourhood, meant people did not need support staff to drive them to places.

People in Shared Lives homes attended day centres. We felt this reduced some benefits of living in a family home.

Researchers spent time in a Shared Lives Day Centre. People of different ages spent time indoors doing activities that might not interest them.

*Day activity **hubs'** location and transport links*
Researchers spent time in 2 day activity hubs, run by the same organisation.

One was in a town centre with easy access to shopping and leisure activities.

Researchers saw a lively atmosphere, with people coming and going. The hub felt welcoming.

The main space was a large open room with friendly and caring staff.

The reception area was mainly staffed by people using the hub.

The **managers'** office was next to reception and open to all.

Researchers felt a sense of community, friendliness and familiarity between people who used and worked at the hub.

The second hub was in a business park away from the local community.

People had to be dropped off and picked up. Staff shortages could mean cancelled or missed activities.

This hub was spread across two buildings with small rooms which meant it was harder for people to hang out.

The large, bright kitchen was where people and staff were together.

The importance of who people live with
It was better when people lived on their own or chose who they lived with.

People felt secure when their home was permanent and when they were living alone, or with a partner.

Living alone gave people control over their lives in ways people with learning disabilities have been denied.

Some Supported Living providers thought the right for people to live alone was a matter of social justice.

Researchers found people could be grouped together in Supported Living settings. They did not have control over their lives, or the security of their own space.

When people live in groups, privacy and quiet, is difficult. People may live with strangers. This is no different to institutional care.

We thought this was harmful for older people with learning disabilities, who could find sharing a busy and noisy home stressful.

In the nursing home, staff wondered if it was the right place for one person to live. They worried her actions had an impact on others and said there was nowhere else for her to go.

It was unclear why the person from the local authority buying the support had not addressed this. This difficulty was known about for around ten years.

We saw that past abuse and institutionalisation led to conflict between people living in homes.

How support is organised

Support could be organised in ways that led to a good life in older age. Matching staff with people led to good and consistent relationships.

Good practice meant people were involved in recruiting their staff.

How support was organised reflected how the organisation was run, **it's** values and management practices.

Recruiting and keeping the right staff to support people
Shared Lives aim to match carers with people they support. This means knowing the staff well.

The nursing home aimed to find staff with the right values. They employed staff who were kind and compassionate.

The nursing home were committed to providing consistent staff, so they did not need to rely on agency staff.

We found having staff that knew people well and **'got them'** was key to receiving good support for people who do not talk.

Good, consistent relationships between staff and people was important for people receiving end of life care.

Staff knowing people well was comforting to the person with learning disabilities and family members.

We found management support was key to keeping staff at the nursing home. Positive feedback from families mattered to staff.

It was important nursing home staff had good relationships with professionals from outside the home. They could better support people and ensure health needs were met quickly.

It was important managers were available with an open-door culture.

Where people were well supported by consistent staff, the label of **'behaviours** that challenge **others'** was no longer needed. This was across all the models of support.

The values and culture of organisations
Where organisations put the person being supported at the centre of their decisions, good things happened.

One Supported Living home identified **people's** interests and made them **'champions',** to give them responsibility and develop their skills e.g. Car Parking Champion.

Person centred values were also reflected in the policies, paperwork and documents in each organisation.

We noted some policies included clear value statements and referred to external standards and human rights.

Good policies used clear language and concrete examples.

Respect and a commitment to **people's** wellbeing and safety were essential. Excellent support was ambitious and aspirational.

Where we saw excellent support, we noted active and thoughtful involvement of commissioners, who buy support for the local authority.

Ageing, health and end of life care
We found many services did not have policies about supporting people at the end of their lives.

Thought was given to choices around death and two homes had booklets that asked questions about what the person would like at the end of life.

The Day Activities provider had little focus on death and dying. Even so, researchers saw people talking about planning for ageing, and good relationships between families and social workers.

One Supported Living home focused on remembering people who had died. There was a poster about a housemate who died in the lobby.

Some staff received training in end-of-life care to support people to stay in their homes throughout their lives.

Even where policies existed, some participants said staff were not open to discussing death and dying.

One person said he was not allowed to talk about grief when some staff were around. Staff said it was because others might not want to think about death.

Some staff said they were upset by the deaths of people they supported and did not like talking about it.

The nursing home had a good guide to end-of-life care. Their plan focuses on living well and understanding **people's** health may worsen over time.

Staff supported people living in the nursing home to write a will and plan their funerals.

Family members were invited to join staff training in end-of-life care in the nursing home. We felt this helped to make a space where everyone worked together to provide the best support.

One Shared Lives site put things in place so that people who might develop dementia, can remain living with their carer.

This support worked for the person and their carer. It was hard for the person with learning disabilities to understand when others developed dementia. We felt this highlighted the need for clear ways of explaining dementia to people with learning disabilities.

We also saw that Shared Lives carers are ageing themselves.

A Shared Lives coordinator spoke about three carers who supported two people with learning disabilities for over thirty years. The carers were now over 70.

The findings of this research are the same for them as for family carers.

Social factors
Good social opportunities included people seeing family members and being supported to do things in their community.

We found staff needed to earn the trust of family members, and work with them in positive ways.

Activities, age and belonging
Having work or activities linked to what people like doing was important. These helped people feel they belong.

We saw some people did a range of activities they enjoyed.

The Day Activity site offered activities for people to find something they enjoyed doing, including farm group, theatre, baking, Zumba, golf, and pottery.

There were no specific activities for older people. Some activities, such as chair yoga, allowed people with reduced mobility to take part.

We saw at times older people would join in an activity because it was a way to spend time with other people.

Day activity hubs provided a sense of belonging for people. People could stay in touch with their friends and make new friends.

Some people received support in groups. Those groups could play an additional support role to their members. People felt they belonged and looked out for those supported with them.

Understanding and affection in Shared Lives
A key feature of Shared Lives is the information and understanding, love and affection people develop for each other.

We saw humour, banter and thoughtfulness around family life, celebrations and holidays.

Shared Lives carers were flexible, helped by how well they knew the people they supported. People had a strong sense of belonging in their families and community.

People were involved with the wider families of Shared Lives carers, including children and grandparents. They hung out together.

Another source of affection, less seen in other settings, was that people often lived with pets.

Poor practice in Supported Living
We saw that Supported Living included situations with different quality for older people, even where those organisations were seen as excellent earlier in the research.

People were grouped together rather than living in the community with support.

We found two kinds of poor support:

1) The lives of people with learning disabilities were less important than the lives of staff.

   This was shown in inflexible staff routines and staff shortages which meant activities were delayed, cancelled or cut short.

2) Support provided was minimal leaving people safe but living lives of boredom.

   People spent days inside with the TV on and others were put to bed as early as 5pm, with only a radio for company.

This is troubling given our sites were chosen because of **'good'** reputations.

Small organisations could support people well due to managers supporting staff. Larger organisations provided excellent support for some and poor support for others.

We saw actions that were not person centred e.g. regular rental inspections of **people's 'homes'.**

The same organisation changed **people's** key worker changed every six months to stop people becoming dependent on a staff member.

This site also used agency staff which concerned a family carer.

New inner-city nursing home
The new service was being designed against national policy and examples of good practice we saw elsewhere in this research.

The plans involved three types of support for the ten-bed household:

1) nursing care for people with complex needs

2) respite care for people needing clinical support

3) sheltered housing flats for people moving to residential care.

The researchers attended a co-design group where there was disagreement between providing ten local beds for older people and criticising the model of care on offer (a large nursing care home).

Support for people should not be provided in institutions. The institutional care on offer was seen as acceptable to help people live near their family, friends and familiar places.

We saw those from the local authority responsible for buying care, family carers and designers working together to overcome these dilemmas.

There was no evidence people with learning disabilities were involved in this process, although we were told they would be in the future.

We saw there was a gap in research about the best practice in housing support for older people with learning disabilities and complex health needs.

So what?

In Chapter 1 we talked about how people with learning disabilities should be supported to age well.

We found little evidence of thinking about how people grow older, outside of the nursing home setting.

People did not have the same opportunities in life as others.

People's lives did not follow the pattern of work, relationships and retirement. This meant there were no obvious markers of time passing.

A lot is written about **'transitioning'** to adult services, but adults face years of sameness.

The ill-health or death of a family carer may be one of the few things that makes visible the ageing of people with learning disabilities.

This means there is no planning for people to age actively, in a home with good support and have a life.

Researchers went to sites that were described as excellent. After hanging out with people, they found important things that shaped support.

Excellence was found where **people's** lives were visibly growing (in different ways).

Excellence was where people were supported to live on their own terms, to grow and expand relationships, interests and aspirations.

We also found evidence of constrained lives, where people were not given opportunities for growth, within services identified as excellent.

This suggests a gap between those who buy services, and what they know about the lives of people supported in those services.

Importance of finding and keeping the right staff
Staff consistency was key to providing excellent support. This was a result of good organisational values and approach to recruitment.

Carefully matching people to staff was important. Involving people with learning disabilities and families in recruitment was key.

Best support was when boundaries between people appeared blurred, where there was genuine affection.

Organisations that did this well included people and worked to avoid '**us** and **them**' cultures developing.

Staff went beyond what was expected of them, such as spending time with people in hospital outside working hours. Good staff also worked to support people to be listened to.

Organisations that relied on agency staff risk staff not knowing people well and returning to institutional type support.

Excellent providers actively avoided using agency staff. They felt this was their responsibility, to ensure social justice for people.

Smaller organisations were better able to get to know people they supported. Shared Lives carers were also carefully matched.

The approach to end-of-life care in the nursing home impressed the researchers. The focus on people living a full life and anticipating health challenges as people got older was key.

We felt local authority staff who bought support for people focused on what things cost, not what was excellent.

Thinking about the label '***behaviours*** *that challenge* ***others***'
We found a mixture of approaches to using the label '**behaviours** that challenge **others**' in the places we visited.

When we looked at their documents and spoke with organisations, they appeared to understand that '**behaviours** that challenge **others**' depended on the situation people found themselves.

They understood they were an outcome of needs not being met.

Despite this understanding, organisations spent staff time, energy and resource on **'positive** behaviour **support'** interventions.

These are approaches that are supposed to **'deal'** with **'behaviours** that challenge **others'.**

These approaches suggest there is something wrong with the person. The same person who people apparently understand is just responding to the situation they find themselves in.

There are risks to people being given this label. Genuine distress can be overlooked, and people may receive less good care.

That **'behaviours** that challenge **others'** can disappear with good support, suggests it is the support that is challenging not the behaviours or people.

Chapter 6. Working with older people and their families to produce and test resources to help prepare people for carers ageing and dying

- We wanted to find out what is important to older people with learning disabilities and their family carers.

- We wanted to make and test resources to help families prepare for the future, including end of life care for carers.

- We found out what approaches older people and family carers prefer.

- We designed and tested a set of discussion cards for families.

Introduction

When older family carers plan their end of life, they worry who will support their relative with learning disabilities.

Research shows little future planning happens.

We worked with people and family carers to make Planning Ahead cards. These have pictures and questions to help people plan a good life.

There were three stages to this work:

1) We spoke to older people and their family members.

2) We developed a set of cards through 12 online meetings.

3) Another 8 families tested the cards so we could improve them.

Stage 1: Understanding **people's** experiences, hopes and concerns about planning.

We wanted to know what older people with learning disabilities living with family thought about planning for the future.

What we did

We spoke to 36 people in groups and individually.

32 people were White/White British, 3 were Black/Black British and 1 was Asian/Asian British.

People could choose an online interview or an in person focus group.

Research shows focus groups can help people with learning disabilities feel supported to share their opinions and hear **others'** experiences.

Who	Number	Average age
Older people who lived with their parents	9	46
Parents who lived with their relative with learning disabilities	11	73
Sisters and brothers of people living with their parents	9	50
Sisters and brothers of people who lived with parents until they were 35+ and whose circumstances changed after parental death or otherwise	7	61

University researchers and a researcher with lived experience did the interviews.

They spoke to people two or three times, so they were comfortable.

We used picture books and communication aids to help people take part.

We looked carefully at the information we collected and sorted it into groups.

What we found
Families knew they needed to plan and worried about the future.

Some thought about what would happen at the end of their life. Others ignored the issue.

People had clear ideas about what they would like to happen in the future.

Family carers did not know what options were available. Some were convinced there were no suitable options.

What mattered to people?
People's main concern was what older people with learning disabilities wanted and needed for a good and happy life.

Having control and independence and being valued, were essential.

    1) Control and independence

Some thought moving from parents was an opportunity to gain independence.

Others thought moving could be a threat to independence and control.

Not being able to do things they loved was a concern for everyone.
Most people liked the idea of living on their own or with family.

Some people had negative experiences of living with others.

Others worried about the stress or difficulties of house sharing.

This is the same as we found in Chapter 5.

2) Being valued

People with learning disabilities were valued family members.

People worried support would lead to people feeling institutionalised.

People said it was important to spend time with people they love.

Some people found it difficult living with parents. They thought family was important and wanted regular contact if they moved.

What people did not know
People asked when planning should happen, what options were available and who could help with planning.

1) When should we plan?

Families were aware of the need to plan but how urgent this felt, varied.

Some carers dreaded what would happen when they died.

Some were desperate to find a solution.

Others found the fear too overwhelming to think about and tried to delay any possible crisis.

Many sisters and brothers said they worried their parents would keep going until a crisis occurred. They found it hard to talk to their parents about this.

Some carers felt there was no point planning while things were ok.

Some people with learning disabilities said this was frustrating, they wanted to take risks and be more independent.

People did not know how much funding there would be or support available.

Some parents were starting to plan and make changes in their lives as they struggled to give support as they aged.
This included supporting people to be more independent. Sisters and brothers were aware of this need.

2) What are the options?

People said living alone with support was the best option, either in a flat or their family home after their parents died.

People needed to understand what was possible and how it might work.

There was little information available.

Parents of people with profound learning disabilities worried they would be pushed towards residential care.

   3) Who will help?

People said they knew social care would need to be involved.

They described this as a barrier to overcome, not a help or support.

Experiences with social care varied and people worried about the lack of knowledge social care staff had about people with learning disabilities.

People said social workers dealt with crises rather than preventing them.

Valuing the person with learning disabilities was key to a good life.

Families of people with profound learning disabilities worried most about who would support them.

People worried without family support; their social lives would end.

Stage 2: Working together to design resources to support older people and their families prepare for the future

We wanted to produce resources to help older people who live at home with family to plan ahead.

We did this with people working with us. This is called co-design.

We held workshops for people taking part in the research, called co-design workshops.

We met 12 times online for two hours.

A film was used to get people thinking. It was made from parts of interviews we did earlier. It covered the following things:

- When should we plan?
- What are the options?
- Can I keep my independence?
- Who will help us to make plans?

- Will it work?
- Who will support us in the future?

Easy read questionnaires were shared after the third session and last session to get feedback.

Eleven people agreed to take part and eight people regularly attended.

The eight included four older people with learning disabilities and four parents. Two sets of families took part together, with a person with learning disabilities and their parent involved.

The workshops were divided into different topics and activities.

Session	Topic
1, 2	Getting to know each other and watching the film
3, 4, 5	Thinking about what the resources could look like and cover
6	Guest speaker: someone who lived in Shared Lives, and their Shared Lives carer
7	Guest speaker: someone who had support from a community-based learning disability service, and the head of the service
8	Guest speaker: A social worker
9	Guest speaker: Head of an organisation that supports people with learning disabilities to use 'life planning'
10, 11, 12	Finishing the resources, meeting with the artist and providing feedback

After the last session, people decided to have a celebration event.

What was designed by the group

The group wanted to make a set of cards to help people think and talk about important things to tell social workers.

They decided to include conversation cards, and information cards.

They also wanted a place to write things down.

They decided to have drawings rather than symbols. They decided to keep drawings and writing in separate boxes.

They decided what topics the cards should cover. They decided what prompts would be asked on the cards.

They agreed how they liked the pictures to look. They wanted black and white images.

The group gave feedback on font size and words.

They agreed the cards should be called Planning Ahead Cards. They also wanted a booklet for notes called Me and My Plans.

There are 102 Planning Ahead Cards. They are available in printed form and online https://sway.office.com/5LjAwIV0OFsHjBAj

Cards are A5 in size and include a picture, label and discussion prompts.

There are seven groups of cards:

- Things I like to do
- Things I might need help with
- Home: what is important?
- People in my life
- About me
- Family carers getting ill or dying
- Information cards

An example card:

Coping with periods or menopause
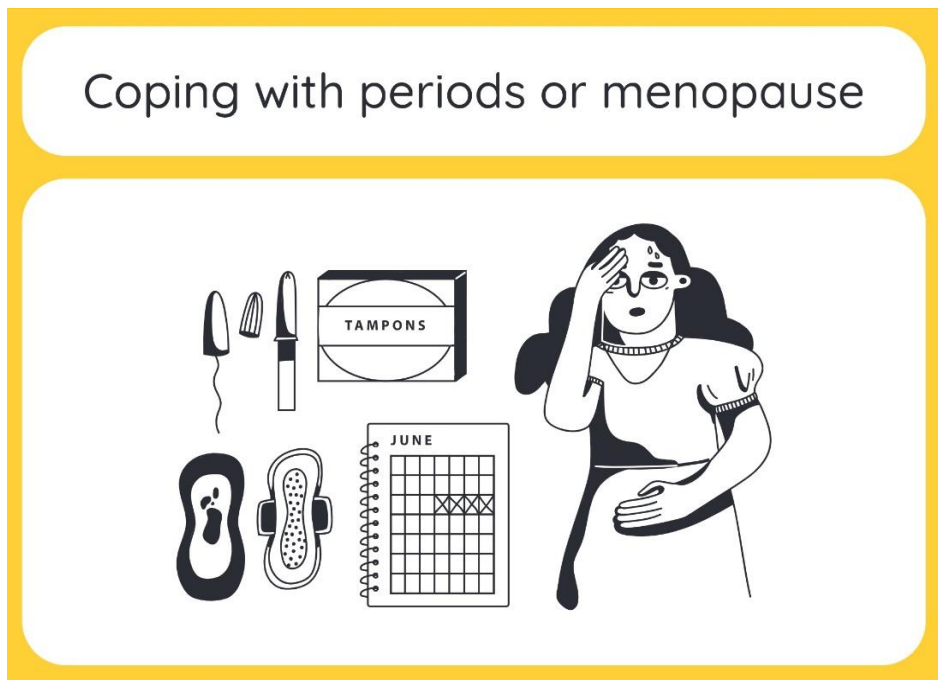
Coping with periods or menopause

What do you need help with?
- Do you need help coping with periods?
  For example:
  - Changing pads or tampons
  - Coping with pain or mood changes
- Do you need help coping with the menopause?
  For example:
  - Understanding symptoms
  - Managing symptoms like hot flushes or night sweats
  - Managing changes to your mood
  - Help talking to the doctor, for example getting HRT

What would happen if you don't get this help?
For example: untreated pain and other symptoms, being unhygienic, being confused about what's happening to your body

Thoughts on working together to design resources
We thought about how we worked together with people and their family members.

Meetings were online due to people living far away and concerns about covid.

A message group was set up for people to keep in touch in the final months of the project. It would have been better if it was done earlier.

Being flexible was key to the success.

The time for workshops was extended to allow feedback on the artist's work.

Not planning everything at the beginning was to allow sessions to be organised in the best way e.g. deciding which guest speakers to invite.

Some group members felt uncertain about what was happening due to this flexibility. Updates should have been shared regularly.

Having a researcher with lived experience facilitating the group sessions was important.

Having people and their parents working together allowed some people to share their perspectives.

Group members liked the sessions with guest speakers. Speaking with professionals and people who used services was important.

Stage 3: Introducing the Planning Ahead cards and seeing what people thought of them

What we wanted to know
We wanted to find out if the cards worked.

What we did

We gave the cards to people to try out. We held feedback sessions.

1) Gathering family feedback

Eight families of people aged over 35, living at home were invited to take part.

People with learning disabilities were included if they could take part and wanted to.

Seven parents, one sister and brother, and four people with learning disabilities took part (12 people in total).

Families were sent the cards, with two questionnaires, one to fill out before they used the cards, and one each time they used them.

Families were asked to use the cards at least once within the two-month period.

Families were sent another questionnaire after two months which focused on whether their plans were influenced by the cards.

2) Gathering feedback from other groups

Four groups of people with learning disabilities and the advisory group also provided feedback.

They were asked to feedback on three questions:
1) how useful they thought the cards would be
2) how they might be used
3) what changes might be needed.

What we found

1) Feedback on the cards design and content

People liked the design and content of the cards, particularly the size, bright colours and pictures.

They said the number of cards could be overwhelming but chose the cards most relevant to them.

They felt that they covered a good range of topics.

The prompts on the back of cards were useful and helped families think about details they might not have thought of.

The **'Mum** and Dad getting ill or **dying'** cards were difficult to look at, but families felt it was an important topic to cover.

The prompts on the back of the cards were not accessible to people with learning disabilities, so they could not use them without support.

We designed the cards to be used by families, but some people wanted to look at them alone.

Some parents felt they would be easier to use if the prompts were easier to understand.

2) Feedback on how the cards might help future planning

People said that the cards could help families make plans.

We looked at the information collected on the questionnaires. The scores suggested little change in how prepared people felt, but when people gave fuller answers, there was some change.

Some scores improved suggesting people felt more prepared about certain aspects after using the cards.

Other scores suggested people were more concerned and less prepared after using the cards.

The cards made people think about future things they might not have thought of before.

Some cards, such as those in **'things** I like to **do',** led to talk that prompted immediate changes, such as planning to go on holiday or try new foods.

The cards got families talking about longer term plans, including where the person may live and what is needed to achieve this.

Some people suggested the cards be used with social workers to make sure plans were put in place.

There was frustration there was no support for this already.

What changes were made after the feedback
We did not want to lose detail in the prompt questions, despite some people finding it hard to understand.

To sort this, question cards were developed with 2-4 simple questions for each topic set which could be used instead of the prompts.

Information about how to use the cards was made clearer.
Information was added to show how professionals could be involved in using the cards.

We will work with organisations to make sure the cards are widely available for use.

So, what does it all mean?

Older people and their families were aware they needed to plan ahead, and many had tried to.

They faced many barriers to making changes and had not received the support they needed to do so.

1) What people want and need

The biggest barrier was not knowing what options would allow people to live good lives, where they were valued and had independence.

Moving from family should lead to more independence and control over their lives.

People and their families were concerned it could have the opposite effect.

They worried people would not get the right support to choose what they do, who they do it with and when they do it.

People wanted to live alone or with a partner. They wanted to be near family and friends. They wanted to be supported by people who know them well and cared for them.

This was very similar to what we found out in Chapter 5.

Families felt that support was out of reach, and this could stop parents making plans.

In Chapter 5 we found examples of good support, but also poor practice. This suggests families' fears may be well-founded.

2) The process of planning for the future

People and their families need information and support to plan ahead.

People worried they would be slotted into services rather than having support tailored to them.

Families worried, especially those with a loved one with profound learning disability, that residential care would be their only option. Something researchers have found before.

Families wanted information about different types of support and examples of where people live good lives, supported by people who knew them well.

The research found a lack of professional support for making plans.

Conversations with social care staff were seen as a barrier to get past rather than help with planning.

Feedback suggested help was only available in a crisis, which reflects what we found in the reviews in Chapter 2.

3) Planning Ahead Cards

People wanted to develop resources to give people and their families the confidence to tell social workers what they wanted and needed.

The cards are designed to start conversations within families. They highlight what is important to people and what they need.

The cards will help people make their case to social care staff about why what they need is important and should be supported.

The testing of the cards suggested they have potential to be a helpful first step for people who want to make changes in the future.

Conclusion
This part of the research highlighted the challenges people with learning disabilities and their families face in planning ahead.

People should be supported to live independent lives, well in advance of their parents becoming too old to care for them.

Many families worried they would not be able to make this happen and would only receive help once a crisis occurred.

The Planning Ahead Cards are a starting point for conversations, but much more is needed.

People need to know there are suitable alternatives, that provide excellent support, so they can choose an option that will enable them to live in the way they want and need.

Chapter 7. Working together to produce resources and training materials

- We held workshops with different people to produce project recommendations.
- We shared easy read resources with self-advocacy groups so they could join in this work.
- We share the issues talked about in the workshops.
- We describe two resources produced to help professionals and family carers to support older people with learning disabilities.

Introduction
This chapter talks about the two events held to talk to people about what the research found.

What we wanted to know
How best to share the information from the research, with people with learning disabilities, family carers and those who worked with them.

What we did
We held two events. The first in Manchester with people attending in person and online, and a second online event.

The discussions from the first event were talked about further and developed in the second event.

45 people attended the first event (16 people online, 29 in person). 32 people attended the second event.

People came from self-advocacy groups, family carers, disability charities, NHS England, CQC, healthcare trusts and local authorities, service providers, people who buy services and academics.

People involved in the research also attended.

Event format
We started by introducing the study and the work done so far.

To get people talking, we asked what excuses they heard for poor support and practice.

Two short films were shown which covered what had been learnt so far.

People were split into small groups and asked to discuss questions from the research.

At event 1 these questions were:
- Where are the social workers?
- Why are families still so concerned about the future?
- Why is good support still so rare?
- Who is responsible for older people without family?
- Why is there so little focus on people ageing?

At event 2 the questions were:
- How do you know if support is good or excellent?
- What helps you to know that or could help you?
- Why did our research find poor practice?
- Who is responsible for making sure people have good lives?

Some discussion was similar at both events.

What people said

Where are the social workers?

People said there were pressures in social work, including poor pay and conditions. The role now focused on helping crises.

It was not known if social workers were responsible for organising support for people as they grow older.

Why are families still so concerned about the future?

People wanted us to know most families love and care about their relatives. They are also scared to think ahead.

People heard about abuse in social care services and or had bad experiences, so had little trust in services.

People worried they would be blocked from their **relatives'** lives.

Why is good support still so rare?

People said there was not enough resources, and what was available was shared unevenly.

Poor pay and conditions for social care staff meant they went to work in other jobs. There were concerns about poor cultures and poor leadership.

Not enough people knew what was available, or what good looked like. People thought stories about good experiences should be shared.

People thought workers should be employed based on their values and that would lead to better organisational cultures.

Some people thought because people with learning disabilities often do not work, there was no recognition they were growing older, and changing support needs could be misunderstood as **'going backwards'.**

Others thought the lack of good support was down to staff members.

> *Who is responsible for older people without family?*

Answers included people with learning disabilities themselves, the State and an ambition that all of us would take responsibility, although it was felt this did not happen.

People talked about unsupportive families, or families who **don't** trust social care services. There was talk about older people with learning disabilities relying on family members and vice versa as they get older.

People said that the law (Care Act wellbeing and preventative strategies) was not working for older people with learning disabilities.

> *Why is there so little focus on people ageing?*

People agreed there is an assumption people with learning disabilities do not grow older.

People said a focus on independence as a goal made it difficult when people needed more help as they got older.

There was concern this was seen as services failing, rather than an aspect of growing older.

> *How do you know support is good or excellent?*

Feedback from people with learning disabilities and families was important, and knowing what services did with that feedback.
Watching relationships between people with learning disabilities and staff was important, alongside asking people if they were happy.

People said other things were important including:

- the language people used
- whether people showed affection
- whether people focused on the person with learning disabilities
- whether people were supported to learn new skills
- whether people were supported to be part of their local community.

Some people suggested asking people who managed services, but others pointed out you need to experience good support before you can recognise it.

What helps people find good or excellent examples of support?

People said sharing knowledge and knowing what is important to people.

Employing people with lived experience as Quality Checkers to identify good practice.

People again asked what happens to people without family.

Why did researchers find poor support in services judged to be excellent?

This was a very important question and people had many ideas about it.

Some said about the lack of ambition and aspiration about the lives of people. Staff could do very little with people, and staff who joined since covid might think this was acceptable.

People said different groups, such as those buying services, may have different priorities to those using services.

People discussed the lack of knowledge some people buying services have about the reality of life in those services.

Commissioners, who buy services, said that it was not practical for them to spend time in services, given how many they were responsible for.

People suggested commissioners and social workers could work together, e.g. by asking 'We've noticed that this is an issue, how can we support you?"

The issue of resources to buy services and staff being well matched to a person with learning disabilities were raised again.

Family members might accept poor support because they don't want to disrupt the person. Sometimes part of a service may not be good.

Who is responsible for making sure people have good lives?

Some people said 'all of us', when asked who that meant, suggestions included local and national politicians, those who buy services, social workers, people with learning disabilities and family members.

The reality of something being **everyone's** responsibility, means no one person is responsible in practice.

People felt that it was not family members responsibility for **someone's** life chances throughout their life.

Good leadership, people working together, and shared responsibility were also mentioned.

What it all meant
We grouped together what people told us into recommendations to improve things. These are included in Chapter 9.

What we did next
We wanted to make sure people with learning disabilities shared their thoughts about the recommendations.

We produced three one-hour session plans for self-advocacy groups to use to discuss the research and what we found.

The sessions focused on how to grow older well, how to plan ahead and how those providing services can do better.

Each session had an activity like a word search, information about the topic, and discussion.

The plans were shared with seven self-advocacy groups. One group sent feedback.

Their feedback was like what was discussed in the events. Extra issues were highlighted about people who cannot rely on family for support and advocacy.

Additional recommendations from the sessions were:
- Focus on healthy ageing, promotion of health checks, GP appointments and follow ups.
- Increase awareness of health inequalities, healthy nutrition and physical activity.
- Staff should be recruited based on how they think and behave. Staff should be kind, encouraging and knowledgeable.
- Staff should be able to have difficult conversations and build good relationships with those they support.

- People should be able to try services before committing to them, to support choice and ensure people are not stuck with support not well matched to them.

A third event

This event was held online with 22 people with learning disabilities, family carers and self-advocacy groups from the north of England.

The purpose was to share findings, discuss the recommendations, and find out what attendees' local priorities are.

Before the event a document was shared called Things that matter? and people were asked to think about their priorities.

The two short films were shown and discussion included:
- Organisations that encourage thinking about growing older said those buying services would not fund accommodation that met **people's** needs.
- Word of mouth was important in sharing good services. People said providers had '**glossy brochures'** but they needed to try things out.
- Those buying services can become stuck on a type of support, rather than offering choices.
- The question who is responsible for coordinating support came up again and again.
- Waiting lists for social workers if someone wants to move home. Some people knew where they wanted to go but people who buy services **wouldn't** spend that much money or told people they were not eligible for support.
- Decisions could take years.

When asked what matters people said it was important to be supported to stay healthy, to live in a house you choose with people you like and be supported by people who know and like you.

Some people do not have family members.

People raised the importance of friendships beyond support staff, and intimate relationships.

People wanted to work, in paid or voluntary jobs.

Some people thought there should be a Minister for People with Learning Disabilities.

Older people with learning disabilities are excluded from support for older people without learning disabilities.

Asked what they would like to see addressed in future research people said:
- Transport in rural areas
- Home ownership for people with learning disabilities
- Importance of pet ownership
- Importance of friendships and intimate relationships
- Loneliness among older people with learning disabilities
- Difficulties accessing support for older people
- Employment rights and benefit related issues.

Online learning resources

The findings from the work spent hanging out with people with purpose were made into online learning resources.

These resources are hosted on the Open University OpenLearn website.

One course is for people working in health and social care, and the other for family carers of older people with learning disabilities.

The resources were developed using what people said in interviews and what the researchers saw when they spent time with people.

Findings were organised around three themes:
1) Supporting people to live well
2) Supporting people to age well
3) A caring culture.

An animation, featuring a quilt was developed, to help explain when all these themes were considered, good practice was the result.

The online resources include filmed interviews with a family carer and a community learning disability nurse. They discuss how they found the resources and offer their personal and professional thoughts.

You can find these resources here:

https://www.open.edu/openlearn/health-sports-psychology/caring-older-family-member-learning-disabilities/content-section-overview?active-tab=description-tab

https://www.open.edu/openlearn/health-sports-psychology/supporting-older-people-learning-disabilities-and-their-families/content-section-overview?active-tab=description-tab

Chapter 8. Public involvement in the research

- We discuss how people were involved in the research.
- The contribution of the public involvement lead who is a family carer.
- The role of the Public Advisory Group.

A public involvement lead, Angeli Vaid, was also a family carer.

> "This project has brought people with learning disabilities, family carers and paid support workers together as participants, whilst also providing an opportunity for people with lived experience to work as partners (that is public representatives). We have been involved from the start of this research - in the earliest conversations to shape the research proposal. We have been welcomed, encouraged and supported by the study team and made decisions across all five work packages at every stage in the research pathway."

Proposal development

The idea for the research came from people with learning disabilities and their family carers who were involved in an earlier project.

The Embolden Project was funded by the National Lottery and lead by Oxford Family Support Network (OxFSN).

The project looked at the experiences of older family carers aged 70+.

Prof Ryan and Angeli Vaid were involved with the Embolden project.

The Embolden Project found failings in social care; older family carers were not known about; their needs were not anticipated.

People with learning disabilities and family carers were involved in developing the proposal for this research. Two people with learning disabilities and one family carer were co-applicants.

Support was included in the proposal to make sure they could be part of the project.

Public Advisory Group and Study Steering Committee

A Public Advisory Group of four family carers and three self-advocates was chaired by Angeli Vaid.

Members shared information about themselves to get to know each other and support each other.

One member did not like the term carer, preferring **'life enabler'.** This reflected their belief that good support is built on relationships of mutual respect.

After a first meeting involving everyone, smaller meetings were held to make them more accessible.

The Study Steering Committee included an autistic public member and checked the research was happening as it should.

Greater Manchester Growing Older with Learning Disabilities (GM Gold)

GM Gold are a group of 15 older people with learning disabilities and their supporters.

The group was set up in 2019 at Manchester Metropolitan University.

This study drew on the experiences of GM Gold members throughout.

Researchers with learning disabilities

Eight self-advocates did the ethnography training to work as researchers, along with Angeli Vaid.

A researcher with learning disabilities worked with the team who made the Planning Ahead cards.

It was difficult to get the person appointed as a researcher within the university, which they have written about.

Training provided to public members of the research team

A session was held to help public co-applicants understand the value and importance of taking part in research and think about ethical issues.

Key members of the team attended online Easy Read training.

Training was provided to people working as researchers. This was developed with money from NIHR School for Primary Care Research.

Four online research training sessions were attended by three self-advocate team members and three people with learning disabilities.

How people were involved throughout the study

Several steps were taken so that people could contribute to the research.

At the start of meetings an Easy Read Slide was shown to remind people what the project was about, where we were at, and the focus of the meeting. Information was presented with pictures We began to present more clearly with photographs, Easy Read and plain English.

More online meetings were held if people felt there was not enough time in a meeting for them to be fully involved.

Record of what was covered in the meeting were in written and audio form. All team members liked having the two versions.

What contributions people made to the research
People also played specific roles listed in the table below.

Focus of the work	Contribution
Staff recruitment	Co-applicants with learning disabilities were on the interview panel for project researchers.
Literature reviews	Angeli Vaid commented on the plan for what and where we were going to search. Advisory Group members recommended we kept findings separate when we considered combining the reviews. This was to make it easier to communicate key messages.
Spending time in examples of good practice / focus groups to develop Planning Ahead cards	Public Advisory Group and GM Gold provided input including on: • wording of interview questions • things researchers should remember when visiting **people's** homes • researchers providing information about themselves to people before spending time in their homes • Checking in with people after they take part in the research • Support for researchers with learning disabilities to travel • The format and design of the Planning Ahead cards.
Study sites recruitment and retention	The Advisory Group were key to keeping a site that temporarily withdrew because of Covid-19 pressures. They suggested working with provider and offering support to make it easier for them to take part in the research. Vaid took part in a promotion video and sent materials out via a carers organisation to help recruitment. Public members encouraged us to change the inclusion criteria to include more people
Working together to develop resources and training materials	Public members played a key role in the three events and chaired the first two. They contributed to the development of the resources used in the events.
Advising on communications	Public members commented on Easy Read briefing sheets, a press release, and magazine article.

Benefits of people with learning disabilities working as researchers

There were three benefits of people working as researchers:

1) People asked questions other researchers would not have thought of.

2) One researcher knew people at a fieldwork site. This helped the team to gain access and people to trust them.

3) One focus group participant asked the researcher about his experiences of Supported Living. They had a good chat.

What difficulties were faced and what we learned

We learned we need to be open to new ways of working to make sure public contributors could fully engage.

Being able to contribute

We sought feedback to identify what could be improved.

Advisory Meetings were evaluated to make them more accessible.

Some researchers with learning disabilities said things moved too quickly in meetings, and they did **"more** listening and less **contributing".**

They would have liked face to face meetings, especially at the start. More in person events and meetings took place later in the project.

Getting people employed and paid

The research funder, NIHR, gave access to a **citizens'** benefits advice service. Four researchers with learning disabilities attended to check their benefits would not be affected by being paid.

The Project Manager sent forms to the Department of Work and Pensions, with initial invoices, to take some of the work off people.

University systems for registering people to work and paying people are inaccessible and hard work.

Legal agreements were not available in Easy Read.

Researchers were expected to provide their own insurance, which is expensive and complicated.

The contract was changed to remove this requirement. An Easy Read guide for researchers with learning disabilities was developed.

To get paid people had to enter their bank details online. The Project Manager produced invoices and submitted them on their behalf to support people.

There were delays in sorting contracts and getting people paid.

Communicating with each other and practical arrangements

Communication was key to the success of people being able to contribute.

We thought about communication, and practical arrangements for carrying out fieldwork with researchers with learning disabilities.

Sometimes visits were arranged at short notice to suit the sites, which made it difficult for researchers to manage.

Sometimes visits were cancelled at short notice which was disappointing.

Why public involvement is important in a study like this

Public involvement was essential for the team to ensure the study was accessible to people, to gain the trust of participants and find out what was important to people with learning disabilities.

The team learned lots about the lives of people with learning disabilities, by working alongside them.

Having people with learning disabilities working as researchers also modelled the value and contributions they can make. This was important when visiting people in their homes.

Staff and participants could see that people were valued as team members, and that helped people know their contributions would be valued.

As time went on, members of the public involved in the study, and researchers, were seen to become more confident and involved.

Having a Public Involvement Lead, led to continuity throughout a long project. This role was filled by someone with lived experience, so public contributors could easily relate to them.

Chapter 9. Conclusions and recommendations

- This chapter shares the main research findings and what they mean.

- It talks about the strengths and weaknesses of the project.

- We highlight areas that still need research.

At the start of this report, we reviewed what had been researched about supporting older people with learning disabilities.

There was not very much.

We suggested this might be due to family carers being worried about supporting their relative to move out, and not knowing what support was available.

We also said that this might happen when there was no professional involved, encouraging the conversations or building trust with families.

This study has confirmed this.

It also found older people living great lives, with excellent support.

What we found out

We found several important things out. These are discussed below.

Older people with learning disabilities can be supported to age well

This did not require anything particularly special.

It worked best when people were supported to live alone, or with their partner, in a comfortable and accessible home that worked well for them.

Ideally this home would be in a community, with outside space, where people could have pets if they wanted.

People need support from people they like, who liked them.

Staff need to know the person they support well, and they need to be well matched.

Staff need to work closely with families and make contact with professionals and support services.

Staff need to have the right skills and knowledge to understand and recognise when people change as they age.

How people communicate with each other is important. This includes people with learning disabilities, family members, support workers and other professionals.

To get good support people need to communicate often, and quickly, to share knowledge and ensure good support is in place.

Those who buy services, commissioners, need to know what works well for people to get the right support for them.

Things that help, such as planning for end of life, assessing for dementia and good management, need to be standard practice.

> *People did not recognise, or try to recognise, that people with learning disabilities are growing older*

Not many people knew how to design, buy or deliver services for older people with learning disabilities.

This means there are not enough opportunities for people to lead good lives.

> *Across the board, there was a lack of ambition or hope for better*

We found examples where older people continued to have good lives.

We also found examples of people living constrained lives, where changing needs were unnoticed by social care staff.

There was a lack of ambition, and no expectation things should be better.

Talk about planning ahead tended to happen when people were already older.

Sometimes people relied on older family members for support, whilst they also supported those carers to remain independent.

People have said this is why families do not plan ahead but we did not think this was a good enough explanation.

The government promises that people with learning disabilities can be independent and in control.

For all the strengths of the Shared Lives model, it faces the same challenges as people living at home with older family carers. The use of day centres also led to questions about whether people were living **'ordinary'** lives.

We found well designed day services could enable people to spend time with their friends or peers but did not help people to be part of the community.

The research showed people do not know what good support looks like for older people with learning disabilities.

We found the needs of family carers may override the needs of their relative as people remained at home because their relatives think it is safe and familiar.

This can lead to family carers saying they are disillusioned with social care, and do not trust good support is available.

> *A lack of up-to-date accessible information, resources and support and uncertainty around who is responsible for what*

We found there is a lack of good information about support in local areas, and a lack of knowledge about what **people's** rights are.

We found social workers have an important role in supporting people to move to their own homes, before they develop age-related difficulties.

We found social workers were absent from **people's** lives, and not visible to most families.

We found people were not clear who was responsible for future planning, which meant it often fell to family carers to try and do.

This means older people without family support, are left unsupported.

Family carers feeling stressed was part of the reason this research happened. The study confirms this is their experience and the lack of support explains it.

> *The unhelpfulness of the label* **'behaviours** *that challenge* **others'**

We found using this label was problematic, and that people used it to withhold good support and justify poor practices.

People need to look at what is causing distress, rather than labelling it.

We found the can disappear with good support. This suggests that it is the support that is challenging not the behaviours or the people.

The focus should be on providing quality support and solutions that help people to thrive as they grow older.

> *Finding poor support in services identified as* **'excellent'**

Finding examples of poor support, in places identified as providing **'excellent'** services raises questions about how excellence is identified or monitored.

We were left with questions about how good those who buy services are at checking the quality of the services; how often they check them and what information they collect.

Weaknesses of the research

There were some things that happened that we identified as being weaknesses of the research, stopping it being the best it could be.

The pandemic made it harder to recruit sites to visit and one withdrew. We relied on provider organisations for recruitment resulting in only White British participants. The project was only focused on England.

People may have hidden poor practice and presented their best impression. We felt this was unlikely given the mix of places we visited but it was possible.

The Planning Ahead cards may not be accessible to all people. They need more testing.

Attempts to plan ahead by families may fail due to a lack of options to achieve what people want. We worried about raising **people's** expectations and hopes, that may not be met.

Equality, diversity and inclusion

The early part of the research involved people who work across England in health and social care, in many areas.

The researchers who spent time hanging out with people in their homes only met with white British people, however a more diverse group were included in the focus groups to develop the Planning Ahead cards.

Accessible communication was important throughout the research, and we used Easy Read, video summaries and communication tools to gather **people's** perspectives such as Talking Mats.

All project resources were co-designed with people with learning disabilities and family carers.

One example, the Planning Ahead cards include pictures, large text and illustrations to represent varied ethnic backgrounds and diversity of disability.

The work stream to develop the Planning Ahead cards did not include people without the capacity to consent, which excluded many people.

We tried to address this through the involvement of family members to ensure experiences were included.

What does it all mean? Implications for practice

There is an urgent need for a new national plan for older people with learning disabilities and their family carers.

This plan, or strategy, should include:

- how support is bought or commissioned
- roles and responsibilities of staff including social workers and support staff
- support for how people live and age well
- sustainable and local services to enable people to live and die in their homes and communities.

Other recommendations are about improving health care, matching staff, supporting staff and allowing people to '**try** before they **buy'** to support choice.

Underneath this main finding, there are findings related to three other things:

Improving things and learning from others

- Make good practice known among providers and commissioners.
- Fund self-advocacy groups to support people to make choices locally.
- Listen to people and their families regularly and go out of your way to ensure their voices are heard.

Improving things for people with learning disabilities receiving support

- Make sure people are supported by staff who are well matched to them and like them. Good relationships will mean less staff change.
- Let people try out new services before committing to using them.
- Recruit staff who are kind, encouraging and knowledgeable. Make sure you do what you can to keep those staff.
- Make sure staff know how the small things that they do improve **people's** lives. Celebrate good things.

Ensuring people age well

- Make sure there is a focus on healthy ageing, with regular health checks and follow-up appointments where necessary.
- Increase awareness of health inequalities, healthy nutrition and physical activity.

Project resources and outputs
Resources and outputs from the project are listed at the end of this summary.

Future research needs
Most importantly are the experiences of older people with learning disabilities from diverse ethnic backgrounds.

This requires relationship building with organisations with ethnically diverse membership early in the research design process.

Other areas include:
- supporting people to age well and die in their own homes

- best practice in designing and buying services for older people especially around housing

- the role of social workers in supporting people to plan ahead

- access to pets and nature

- accessing support for older people without learning disabilities

- wider evaluation of the Planning Ahead cards.

Conclusions

There is little research on older people with learning disabilities and family carers.

There is little thought or information about people grow older, so they are not supported to live good and healthy older lives.

Some people were living good lives, in their own homes, with excellent support from staff who knew them well.

Even services which were mostly excellent, varied in how proactive they were in planning for **people's** older age and end of life care.

Families were often unsupported to plan. This means people with learning disabilities are left without choices about their future lives.

The label '**behaviours** that challenge **others'** was unhelpful. It did not lead to discussions about **people's** human rights or what **they'd** like in their care. It did not help when researchers spent time with people and did not feature in the reviews conducted.

Final bits

What does good look like

- Support for the person with goals, plans and updated activities.
- Staff and people being supported are carefully matched.
- Your own personal living space and choice about who this is shared with.
- Active healthcare with the GP and learning disability teams.
- Recruiting staff with the right values and skills.
- Keeping staff in the job so people know who is supporting them well.
- Flexible ways of communicating.

- Family involvement.
- Being part of the community.
- Trauma informed support where appropriate.
- End of life care planning, dementia assessment and management as routine.
- People who buy services know that the service is good.
- People who buy services work with providers, people with learning disabilities and families to develop future services.