

## *Growing older, planning ahead:*

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

### **Briefing paper**

**Work Package 4 - Investigate, co-produce and test a family based support programme to help families living with older people with learning disabilities to prepare for parental loss, transitions in care, and end-of-life care for carers.**

### **Introduction**

This is part of a wider programme of work, '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.' It is funded by the National Institute for Health Research (NIHR 129491). Ethical approval (in process).

Please see Briefing sheet 'Overview' for an overview of the whole project.

Project website <http://wels.open.ac.uk/research/growing-older-planning-ahead>

### **Objective of Work Package 4**

WP4 will look at the experience and needs of families living with older people with learning disabilities to prepare for parental loss, transitions in care, and end-of-life care for carers, and develop and test a support programme.

### **Methods**

This work package, led by Irene Tuffrey-Wijne (Kingston & St George's University), consists of three stages.

In **stage 1** (9 months), we will 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, and what might help them plan for future living options outside the family home. We will talk with members of the Oxford Family Support Network (OxFSN) which is a members group of families with a person with learning disabilities.

**Stage 2** involves six months of fortnightly meetings with a sample of six parents, sisters and/or brothers and six people with learning disabilities to work out solutions and develop a support programme. We 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 us develop resources to help with future planning and decisions ("decision-aids").

During **stage 3** (the final year of the project), we will see how the new decision-aids work for families of people who are at risk of developing behaviours that challenge others. This may include adults with severe or profound learning disabilities. Ten family carers and their adult son/daughter with learning disabilities will be asked to test out the decision-aids as part of their own family decision-making. This final stage will also find out what training and support people need, and who is best from outside the family to support using these decision-aids. We will find out how this works in real time by asking families to use family diaries; researchers will observe meetings and take notes to see how the decision-aids are used and decisions are reached; and we will interview them to find out more about their views. As examples, we may include short films and picture books that help discussion and decisions about the changes in living arrangements and the end of life plans for parents themselves.

The WP4 team is based at Kingston & St George's University in London. Most of the data will be collected in the Oxford area, with researchers travelling to the participants (unless COVID-19 restrictions prevent this, in which case alternative methods will be sought).

The research will include the perspectives of co-researchers who have lived experience of learning disability, and who will be actively involved in gaining the views and in observing the involvement of people with learning disabilities who take part in this research. We will use a range of ways of involving those taking part who live with learning disabilities such as the use of pictures, Books Beyond Words or Talking Mats.

## Data analysis

Thematic analysis will be conducted alongside the fieldwork using constant comparison techniques, aided by memos and mind maps. There will be weekly meetings with the WP4 team, as well as data analysis workshops with the wider research team and the Research Advisory Group, to discuss the data and the interpretation; this includes a co-researcher with learning disabilities.

## Timing

We plan to undertake this work between November 2020 and the end of September 2022, with some flexibility expected due to current pandemic uncertainties.

## Anticipated outputs

A full report; publications in peer-reviewed journals; a film, resources and decision aids, hosted by [socialcaretalk.org](http://socialcaretalk.org) and [OxFSN](http://OxFSN).

## The team

### Work package lead

Prof. Irene Tuffrey-Wijne (Kingston & St George's University, London)

### Co-investigators and researchers

*To be appointed, all at Kingston & St George's University:*

Project manager (Qualitative researcher)

Co-researcher with learning disabilities

### Project coordinator

Dr. Angela Martin (Oxford University)

Email: [angela.martin@phc.ox.ac.uk](mailto:angela.martin@phc.ox.ac.uk)

Web: [wels.open.ac.uk/research/growing-older-planning-ahead](http://wels.open.ac.uk/research/growing-older-planning-ahead)

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