



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 3 - Explore how people with learning disabilities with behaviours that challenge others and their carers can be better supported in later life by researching the commissioning and delivery of innovative supported living services using ethnographic case studies.

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 3

WP3 explores the delivery and characteristics of four exemplar supported living settings services identified in WP2.

Methods

We will study how services in the community support older people with learning disabilities and behaviours that challenge others, family and professional carers and those who provide and commission these services. Methods will include observation over several months, interviewing and studying documents about the services in up to four exemplar providers. Which ones we select will be informed by the findings from the mapping exercise (WP2).

Teams from Oxford University, the Open University and Manchester Metropolitan University, including learning disabled and/or carer co-researchers will work together to explore the four case study sites in depth. Research teams will try to understand how people are supported in their everyday lives, to think about the challenges of getting older, how transitions between different models of care are managed, how issues like death and dying are discussed and how behaviours that challenge others can be prevented or managed better. The research team will spend time with people and staff both within and outside the setting. Each team's co researchers will bring their lived experience of learning disability or caring. The case study site led by Manchester Metropolitan University, for example, will draw on the research team from the Greater Manchester Growing Older

with Learning Disabilities project (GM GOLD). Interviews will explore the reasons why the person with learning disabilities has or will soon be moving away from the family home; what was important to the person and their carer (and support-workers, providers and commissioners); how decisions were arrived at, the relationship between family carers and those they care for, and their views about future planning and end of life care.

The researchers will keep detailed field notes including a description of the setting, interactions between people and staff and with objects and the environment, emotions, impressions and reflections. Finally, we will conduct a documentary review of the provider policies and guidance at each site.

Data analysis

Analysis will be conducted alongside the fieldwork. Our aim is to capture the micro detail in which people and staff express emotions, both positive and negative, and engage with each other and others, while examining what is happening in (and off) these sites and how people and staff make sense of and act in everyday life.

An analysis workshop will be held to bring together the different types of information and discuss these findings with co-researchers and Advisory Group members.

Timing

We plan to undertake this work between January 2021 to end March 2022, with some flexibility expected due to current pandemic uncertainties.

Anticipated outputs

A report to inform WP5, a 20 minute film provisionally titled 'The Good Old Life' of interview audio extracts, photographs and other materials for publication on Socialcaretalk.org, a podcast featuring members of the research team and Advisory Group discussing the research and a peer reviewed paper.

The team

Work package lead

Dr. Sara Ryan (Associate Professor, Sociology, Oxford University)

Co-investigators and researchers

Dr. Liz Tilley (Senior Lecturer, The Open University)

Dr. Melanie Chapman (Research fellow, Manchester Metropolitan University)

Dr. Sue Ledger (Visiting research fellow, The Open University)

Dr. Magdalena Mikulak (Qualitative researcher, Oxford University)

To be appointed (Qualitative researcher, Manchester Metropolitan University)

To be appointed (Co-researcher with learning disabilities, Manchester Metropolitan University)

To be appointed (Co-researcher with learning disabilities or carer, Oxford University)

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