



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 2 - Identify exemplars of good practice in services and support interventions in England for older people with learning disabilities (and their family and professional carers) with behaviours that challenge towards end of life.

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 (OU HREC 3639).

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 2

Working with a range of experts we aim to identify examples of good services and interventions which support older people with learning disabilities to live in the community.

Methods

Working with our networks and the Advisory group we will develop working definitions of:

- (a) service users (currently aged 40 plus with a learning disability) living in the family home, residential or supported accommodation, excluding those in secure or other in-patient facilities.
- (b) services in scope for the mapping exercise: e.g. models of supported living which include service wide interventions to prevent and manage behaviours that challenge others such as positive behavioural support. This research is not examining interventions aimed at specific individuals.
- (c) key characteristics of the services most relevant for older people with learning disabilities and behaviours that challenge others including supporting those towards the end of their lives.

Taking these definitions together, we will map existing services and develop criteria for selecting exemplar services for this group of people.

Sources of data/intelligence about services

There are thousands of relevant services, often with a small number of people who use them. We are not looking to map everything, rather we are looking for “what good care looks like” across England, via NHS networks (such as at regional/transforming care partnership level), directors of adult social services, professional networks (such as via networks of consultant learning disability nurses, BASW, Royal Colleges) and the larger providers (e.g. Dimensions, L’ Arche), and interest groups (such as, Learning Disability England and the Voluntary Organisations Disability Group). We will also work with the CQC to identify exemplars. We will reach out via social media to seek good practice examples from the public.

We will collect data using emails and phone interviews with key people (e.g. managers, clinical leads) to populate a database that captures key features of services.

Mapping

Characteristics: Location (e.g. rural/urban), Provider type (e.g. Private/Voluntary sector); Client base (e.g. focus on people with learning disabilities, or also other older adults); Service models, (e.g. including positive behaviour support approaches for all by home support staff, respite care, palliative care, etc); evidence of “success” (CQC ratings, client/family/ professionals’ views). These are initial examples, as we expect other features will emerge from the data in this study.

We will seek to contact people who know about these services (e.g. senior NHS/social care commissioners, managers, clinicians) to gain the information to map the services and discuss with them the key features of what good looks like. We will interview those they can recommend talking to us about exemplar services at the local level.

The results of the mapping will allow us to identify a short list of services which are exemplars and can be included in a more in-depth case study approach in a separate work package.

Timing

We plan to undertake this work between September 2020 to end January 2021, with some flexibility expected due to current pandemic uncertainties.

Anticipated outputs

Peer reviewed publication, description of services and support interventions for older people with learning disabilities with behaviours that challenge from which case studies will be selected as exemplars (see Work package 3 (wels.open.ac.uk/research/growing-older-planning-ahead)).

The team (see Briefing “Overview of the project” for full research team)

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