



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

Introduction and background

What is the programme about?

An increase in the life expectancy of people with learning disabilities, reductions in the availability of services, and a reluctance on the part of older parent carers to forward plan for their older adult daughter's or son's move to independent supported living or an alternative home can lead to an increased risk of crisis placements. Of 900,000 adults with learning disabilities in England, two thirds live with family and one fifth exhibit 'behaviours that challenge others'. These behaviours are often generated by a change in family or external circumstances, such as when an older carer becomes unwell and unable to continue to provide support. Many older carers worry about their daughter and son's futures and little is known about how carers plan for their own end of life care in the context of many years as a family carer. Policy and services have done little to address this hidden problem.

Our study aims to improve support for family (and professional) carers and older people with learning disabilities with behaviours that challenge others by producing effective and workable recommendations and resources including end of life care planning for carers.

Work packages

Work package 1 will review literature about the health and social care needs, service interventions and resources for (a) older people with learning disabilities and (b) family carers, with a focus on those with behaviours that challenge others. We will also review research on support for older people with learning disabilities at end of life.

Work package 2 will identify exemplars of good practice in residential, supported living and family support services and support interventions in England for older people with learning disabilities (and their family carers) with behaviours that challenge others.

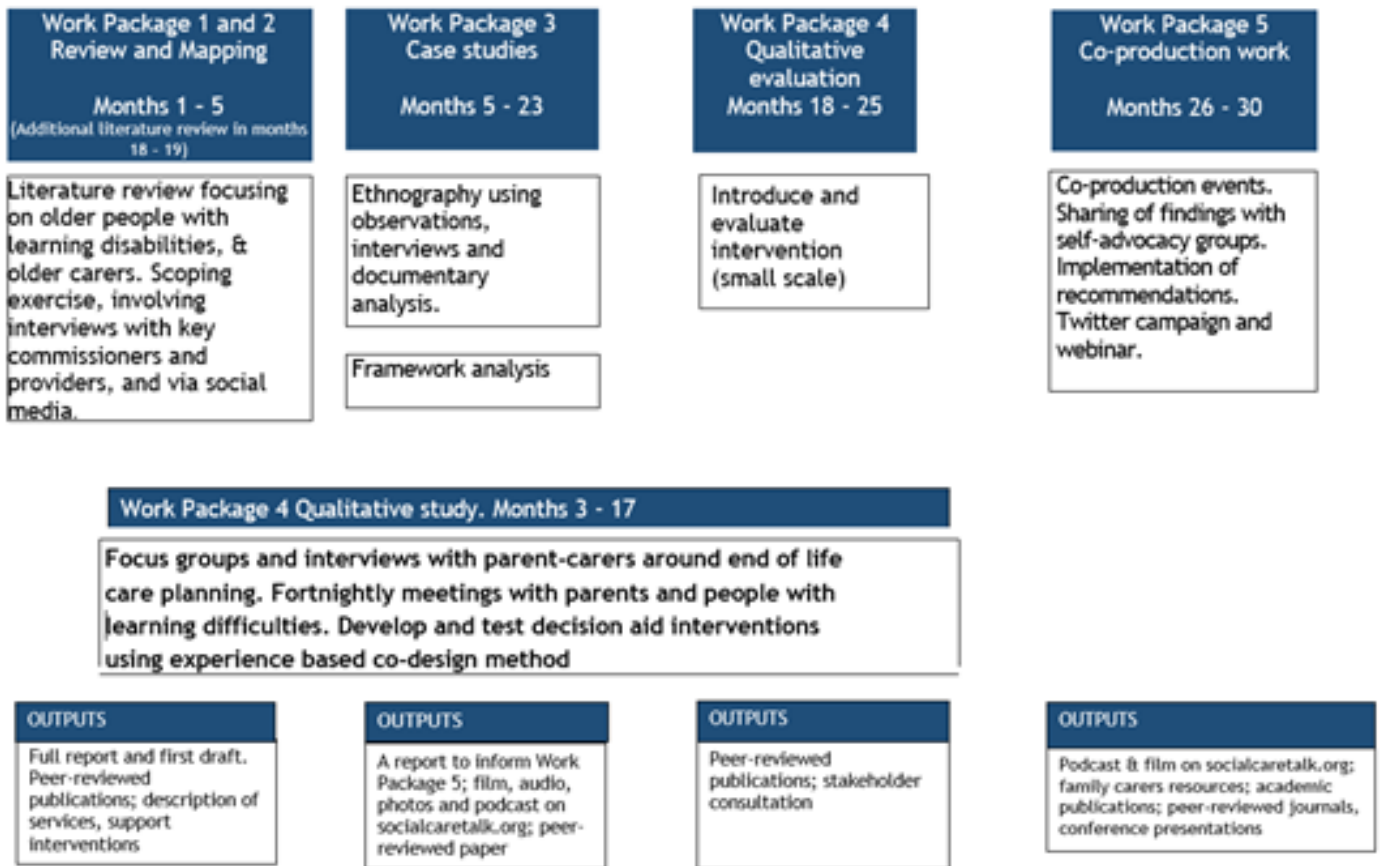
Work package 3 will explore how people with learning disabilities with behaviours that challenge others and their family carers can be better supported in later life by researching the commissioning and delivery of innovative supported living services using ethnographic case studies.

Work package 4 will co-produce decision aid tools to support future planning and end of life care discussions for carers and evaluate their initial use.

Work package 5 will co-produce actionable recommendations for commissioners and providers, resources and decision-aids for family carers and people with learning disabilities with behaviours that challenge others, and free online training materials about caring in later life for the public and for professionals.

Anticipated impact

The main beneficiaries of this work will be older family carers and people with learning disabilities; outputs will promote forward planning by carers and people with learning disabilities. Commissioners and providers will be able to learn from our exemplar case studies to inform commissioning. Professional carers and health and social care staff will benefit from the development of engaging and innovative resources covering issues around ageing, end of life care, forward planning and behaviours that challenge.



The team

Our team comprises carers, self-advocates and researchers with a wealth of experience of qualitative research with a focus on people with learning disabilities and their carers, health and social care services research, health inequalities, intervention evaluation, inclusive research methods, resource development and social work practice.

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