



The DAPPLE Project

Developing effective service models for Adult Palliative and end of life care for People with a Learning disability (DAPPLE)

Scientific Abstract

Aims

To improve quality and accessibility of Palliative and End Of Life Care (PEOLC) for people with a learning disability by producing robust guidance for health and social care services, with recommendations and accessible resources.

Objectives

- (1) Map PEOLC trajectories of people with a learning disability, using national electronic health record data bases
- (2) Develop an understanding of existing evidence
- (3) Explore, compare, and contrast PEOLC services for people with a learning disability, with regards to (a) current models of care, commissioning practices and service coordination; (b) timely identification of PEOLC need; and (c) individualised PEOLC provision/interventions for people with a learning disability
- (4) Co-produce actionable recommendations and resources for service providers and commissioners, including interventions for timely identification of PEOLC need
- (5) Build capacity and produce guidance for future inclusive research with people with a learning disability

Research questions

- What are the service delivery models and interventions within health and social care services that (a) enable timely identification of the palliative and end of life care (PEOLC) needs of people with a learning disability, and (b) are effective in meeting those needs?
- Within a range of service exemplars, what are the barriers and enablers to providing accessible, high quality PEOLC to people with a learning disability; and what are the replicable elements of good practice?

Methods

This is a co-produced study, involving a diverse team (including co-researchers with a learning disability) in academic and service provision settings. There are 4 Work Packages (WP):

WP1: Retrospective cohort analysis of the Clinical Practice Research Datalink (includes 87,790 people with a learning disability), comparing people with and without a learning disability in order to detect inequalities: registration of PEOLC need and subsequent survival time; primary care and hospital care utilisation; palliative care referrals.

WP2: A rapid scoping review to inventorise what is known with regards to (a) identifying need, (b) assessing and meeting need, (c) coordination and delivery of local services and interventions (e.g. staff training).

WP3: Within 4 localities (Study Sites) in England: **(A)** Interviews with commissioners and senior managers in services (n=16), stakeholder conversations and local stakeholder engagement events (n=12); **(B)** Case studies of people with a learning disability currently approaching end of life (n=up to 20), using ethnographic methods; and retrospective case reviews of people with a learning disability who have died (n= up to 40), using family/carer/staff interviews and case file analysis; **(C)** Development and testing of methods for enabling systematic identification of PEOLC need, using Experience-Based Co-Design. **WP4:** PPI activities, engagement and outputs for a wide range of audiences; work with self-advocates with a learning disability to co-produce outputs. **Data analysis and data synthesis** will involve researchers across Study Sites and include co-researchers, using adapted Framework Analysis methodology.

Anticipated impact and dissemination

Outputs include written actionable recommendations and policy guidance; a series of 12 practice exemplars; a logic model; materials for varied audiences (including easy-read); social media activities, website, blogs and webinars; conference presentations; OpenLearn resources for health/social care professionals and carers.

Project website

More information and contact details:
www.dappleproject.com