

The Victoria & Stuart Project:

Co-designing a toolkit of approaches and resources for end-of-life care planning with people with learning disabilities within social care settings

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Scientific Abstract

Aim

To improve personalised end-of-life care provision for people with learning disabilities (PwLD) by co-designing a toolkit of End-Of-Life Care Planning (EOLCP) approaches and resources that are beneficial to PwLD and workable within adult social care services.

Background

National mortality reviews have shown that the deaths of people with learning disabilities (PwLD) are often unplanned for and poorly managed. PwLD are rarely involved in their own end-of-life care planning, and there is insufficient evidence around how to improve this. LD service providers are at the forefront of providing end-of-life support for PwLD but lack skills and confidence in this area.

Research questions

What are the optimal approaches, shared decision-making tools and other resources that enable effective EOLCP with PwLD with a range of needs and in different circumstances, and are welcomed by PwLD, families and staff in adult LD services?

Objectives

1. Inventorise existing approaches and resources;
2. Explore stakeholder preferences;
3. Co-design a toolkit of preferred EOLCP approaches and resources that can be implemented in adult social care services for PwLD;
4. Test the toolkit in practice;
5. Provide a final toolkit of guidance and resources for LD service providers to support EOLCP beyond this project;
6. Build capacity for future inclusive research.

Methods

This is a co-produced research project. Two universities, two major LD services providers (MacIntyre and Dimensions), Voluntary Organisations Disability Group (a membership body representing 100+ disability organisations) and a hospice will share power and responsibility throughout the project, including the generation of knowledge. The research questions have arisen from the LD service providers, PwLD and families. Co-researchers with LD are actively involved at all stages, including on the co-applicant team. The study comprises the following five work packages (WPs):

- WP1 (month 1-6): Rapid scoping review and a national survey of voluntary sector organisations (n=100), to inventorise existing EOLCP resources, approaches and approaches for PwLD.
- WP2 (month 1-6): Exploring stakeholders' experiences and preferences around EOLCP. Nine focus groups with PwLD, families, LD support staff, LD managers and other professionals (n=36-54).
- WP3 (month 7-14): Co-design: a team of 8 PwLD, 2 LD support staff, 2 family carers and a 3 professionals will assess and critically appraise the evidence from WP1 and WP2, and develop a toolkit of testable EOLCP approaches and resources, using adapted Experience-Based Co-Design methodology.
- WP4 (month 15-22): Testing: 30 staff across two LD services will use the preliminary toolkit with PwLD. Evaluation through questionnaires, tester diaries and focus groups. Co-production of final toolkit.
- WP5 (month 1-24): Engagement and impact. Collaborating stakeholders are brought together to ensure engagement with wider communities and service providers. Extensive outreach to social care sector.

Anticipated impact and dissemination

Outputs include EOLCP guidance, resources and training materials, primarily for use within LD services, freely available and disseminated widely through our extensive networks and social media. This will lead to increased staff confidence and skills in EOLCP with PwLD, and increased involvement of PwLD and families in EOLCP. Other professionals, families, commissioners and policy makers will also benefit from engaging with the guidance and innovative resources.

Plain English Summary

An Easy-Read Summary is also available.

There are around a million people with learning disabilities in England, almost two thirds of whom live in residential care or supported living settings when they reach the end of their lives. Staff in learning disability services are therefore at the frontline of end-of-life care provision and planning, but they are often unprepared for this, lacking skills and confidence. People with learning disabilities themselves can find it hard to understand what is happening and are rarely involved in ensuring that end-of-life care is given according to their wishes and preferences. Learning disability services have asked us for help in knowing how to get end-of-life care planning right for the people they support.

Our study aims to improve end-of-life care planning within learning disability services, by investigating what is likely to work best for whom, and producing guidance and resources that are welcomed by people with learning disabilities, families and staff.

We will:

1. Review what is known about end-of-life care planning with people with learning disabilities, and what approaches and resources are already available;
2. Hold focus groups with people with learning disabilities, families and professionals, asking them about their views and preferences;
3. Work together with a team of 8 people with learning disabilities, 2 family carers and 5 professionals to select, and develop further, the preferred approaches and resources that are most likely to work well with a range of people with learning disabilities under different circumstances;
4. Ask 30 staff in learning disability services to test these with the people they support;
5. Create a toolkit of guidance, approaches and resources, as well as staff training materials, and make these freely available online;
6. Create resources to promote and enable future inclusive research.

Our final toolkit will clarify for who and in what situations the approaches and resources are most likely to be beneficial. They are primarily aimed at staff working in adult social care services, but will also be of use for families, people with learning disabilities themselves, and healthcare professionals. Outputs will be in suitable formats aimed at different academic and lay audiences, including easy-read. We have a robust dissemination plan, with allocated time and resources to ensure our project outputs reach the people they are aimed at.

This two-year project is a unique collaboration between researchers based in universities (including researchers with learning disabilities, who have helped plan the project), services that support people with learning disabilities and palliative care services. There is strong engagement with people with learning disabilities, family carer organisations, policy makers and other stakeholders, who will advise the project team throughout.