P-20 SUPPORTING PEOPLE WITH LEARNING DISABILITIES AT END OF LIFE: REGIONAL NETWORK LAUNCH

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People with learning disabilities (PWLD) may experience inadequate end of life care through services not considering individualised needs (Care Quality Commission, 2016). The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD, 2013) reported that coordination in end of life care was limited and improvements are required.

Aim Establish a regional network for people with learning disabilities, carers, self-advocacy groups, clinicians, care homes, hospices and academics. Encourage discussions, conversations, and positive adjustments around death and dying, working alongside and enabling provision of person-centred care tailored to individual needs.

Methods

- Partnership with Birmingham City University;
- Scoped interest of a regional network via Twitter and ehospice;
- Launched May 2019;
- PWLD key network members;
- Engagement via social media using hashtag #LDEOL;
- Pledge cards and world café mind-mapping to collate information.

Results 45 attendees from a mix of backgrounds. 22 additional people requested to join network. World Café questions included 'How could we better support and include PWLD in our community in living well and dying well?'

Feedback

- 'Empower communities to better support PWLD to get involved!'
- 'More community roles, if people are seen, barriers start to break down'
- 'Listening and learning from lived experience'
- 'Identify gaps, have honest conversations and communicate in a way we can all understand'
- 'See the person, not the learning disability'
- 'End of life pathways in all areas'
- 'Change the culture of 'Am I allowed to do this?' and working within own boxes'
- 'Great to hear from PWLD about what is important to them'
- 'Fantastic network launch, looking forward to the next event!'

Conclusion 'Continue to advocate good quality end of life care for everyone'. 'Allow people an open space to hear and understand unique narratives'. Twitter account requested network and share information. Widen network, host events across regional venues. Parallel training opportunities. Set measurable outcomes and write a five year strategy. Develop network charter.

P-21 TRANSFORMING EDUCATION FOR LEARNING DISABILITY STAFF AND ADDRESSING INEQUALITIES IN END OF LIFE CARE

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In a collaborative and innovative approach to tackling inequalities in end of life care, Dr Kershaw's Hospice has developed, delivered and evaluated a successful and bespoke training programme for staff supporting people with learning disabilities (LD) in their own homes and supportive housing.

Through a process of reflective practice and clinical supervision, LD staff from Oldham Care and Support highlighted various challenges they faced in providing end of life care, bereavement and pastoral support to service users and colleagues following the death of a resident. These challenges are further supported by a report commissioned by the Care Quality Commission (2016). Subsequently, an alliance formed between the LD Service Manager and the learning and organisational development team at Dr Kershaw's Hospice to address concerns and challenges.

Evolving from a comprehensive training needs analysis a clear vision emerged, the ultimate goal to transform the knowledge and skills of staff working in the learning disability service around provision of palliative and end of life care; including grief and bereavement support.

The package consists of two full days of training each with a discrete focus. Day 1 centres on clinical issues, i.e. recognition of end of life, symptom control, practicalities of dealing with a death, documentation and processes. Day 2 emphasises a holistic approach looking at emotional resilience, grief and loss, self-care, communication skills and spirituality.

Feedback from initial training days was analytically evaluated and revisions made to subsequent training. The programme runs quarterly with the ambition of excellent palliative and end of life care for people with learning disabilities, improved support for other service users and enhanced staff wellbeing.

Dr Kershaw's Hospice are dedicated to working across professional boundaries to improve the provision of end of life care throughout the borough of Oldham, regardless of the location of care. The future vision is of an adaptable model to providing education for professionals working with all inequality groups.

P-22 DEATH, DYING AND LEARNING DISABILITIES

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Background People with learning disabilities have poorer health than the general population and experience health inequalities in a number of different ways (JSNA Briefing on Learning Disabilities. Worcestershire County Council, 2018). LeDeR (The Learning Disabilities Mortality Review, 2018) suggest a disparity in the age of death for people with learning disabilities and the general population to be 23 years for males and 27 years for females.

Aims Ensure hospice care is seen as an option for people with a learning disability at the end of life with increased external awareness, improved access, internal education and supporting conversations in the community about death and end of life with people with a learning disability.

Methods St Richard's Hospice made three pledges in the SpeakEasy NOW White Paper on Growing Older and End of Life. As a result we have started an internal learning disability working group and work in partnership with SpeakEasy