SUPPORTING PEOPLE WITH LEARNING DISABILITIES AT DEATH, DYING AND LEARNING DISABILITIES

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 e-hospice;
- 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.

DEATH, DYING AND LEARNING DISABILITIES

**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) suggests 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.