Aims

- To understand and identify the needs of those supporting people with learning disabilities from a hospice and learning disability perspective.
- Explore levels of confidence of varying health and social care professionals when talking about death, dying and bereavement to someone with a learning disability.
- Compare and contrast experiences and gaps in knowledge and experiences between hospice and learning disability carers.
- Inform the content and process of the training programme.

Actions

- The project steering group collaboratively developed a survey to establish baseline data and increase knowledge.
- The survey shared with hospice staff and local learning disability organisations.
- Survey thematically analysed outcomes to illustrate similarities and differences within and across data sets.
- The data directly informed the three-session training programme.

Outcomes

- Over 100 responses received, with a near equal split of hospice/non-hospice.
- The replies are being thematically analysed.
- The data directly informed the content and process of the training programme.
- The project is currently being prepared as a paper for publication in a peer reviewed journal to maximise dissemination of outcomes.

Conclusion Learning is key in any project. By conducting the survey, we have learnt much about people's levels of confidence, their understanding, and their training needs. The results of the survey have already influenced the project and when shared more widely, will help us develop a more compassionate community around people with learning disabilities.

P-10

STEPPINGSTONES TO BETTER PRACTICE: LIVING, DYING AND REMEMBERING WITH A LEARNING DISABILITY

Ian Leech. *St Giles Hospice, Lichfield, UK*

10.1136/spcare-2021-Hospice.31

Background We are committed to remaining an inclusive hospice and have adopted a community development approach to respond to national reports and research (LeDeR programme, 2018; Hunt et al., 2019; Heslop, Blair, Fleming et al., 2013; Oliver, 2017) that highlight the need to improve end-of-life care and bereavement support for people with learning disabilities in England.

Aims

- To enable the hospice to effectively monitor patients with learning disabilities accessing services, providing a more patient centred service.
- Develop and support a network of local learning disability champions.
- Deliver targeted, multidisciplinary training on best practice when supporting people with learning disabilities at end-of-life and through bereavement.

Actions

- A local learning disability partner was sourced.

- A steering group, including two members with a learning disability, oversaw the project.
- A survey was developed and distributed.
- Building on the survey outcomes, a focused programme around supporting people with a learning disability at end-of-life was developed and delivered by experienced trainers, in conjunction with two people with a learning disability.
- Champions were recruited to develop and drive the work forward.

Outcomes

- Better hospice systems of recording patients with learning disabilities.
- New relationships with learning disability organisations developed.
- Created a network of learning disability champions who will meet regularly to develop their knowledge; share good practice; and act as a conduit to inform future aspects of end-of-life care with this marginalised group.
- Delivered a three-part training programme (informed by the responses from the survey).

Conclusion Bringing together local learning disability organisations has strengthened our ongoing commitment to develop compassionate communities. By adopting a community development approach to better understand the issues faced by people with learning disabilities at end-of-life and through bereavement, we have already identified issues and changed practice and there is real passion and determination to take this work forward through the network of local learning disability champions.

P-11

'MIND THE GAP' – WIDENING ACCESS TO HOSPICE CARE FOR PEOPLE WITH A LEARNING DISABILITY

Sue Marsden, Eirian Levell, Colin Twomey. *St Wilfrid's Hospice, Eastbourne, UK*

10.1136/spcare-2021-Hospice.32

Background It is recognised that people with a learning disability do not access specialist palliative care services in the same way as their peers without learning disabilities; and that people with a learning disability may need significant reasonable adjustments to enable them to fully access all aspects of end-of-life care. To address this need, our hospice is currently undertaking a year-long project running until early 2022. A grant funded role of Learning Disability Nurse as End of Life Care Facilitator has been established.

The key aims are to:

- Work across hospice and learning disabilities services, to understand and challenge gaps in knowledge and access for people with a learning disability.
- Use the skills of both sets of teams, to support learning, and build sustainable resources, knowledge and relationships across all stages of palliative and end-of-life care – from early identification through to last days and bereavement.
- Engage with local communities, to start conversations about death and dying– to ensure the right support is available for people with a learning disability, their families and carers.

Outcomes

- Gap analysis across hospice and learning disabilities statutory provision to identify training skills and deficits indicates