



Widening access to end of life care for people with Learning Disabilities

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Background

It is known that people with a Learning Disability (LD) do not access Specialist Palliative Care (SPC) services in the same way as their non-Learning-Disabled peers. In addition, people with LD may need reasonable adjustments to enable them to fully access all aspects of end of life care (EOLC).¹

To address this need, St Wilfrid's Hospice is currently undertaking a year long project running until early 2022. The hospice has employed a Learning Disability EOLC Facilitator to work across hospice and LD services



Aims

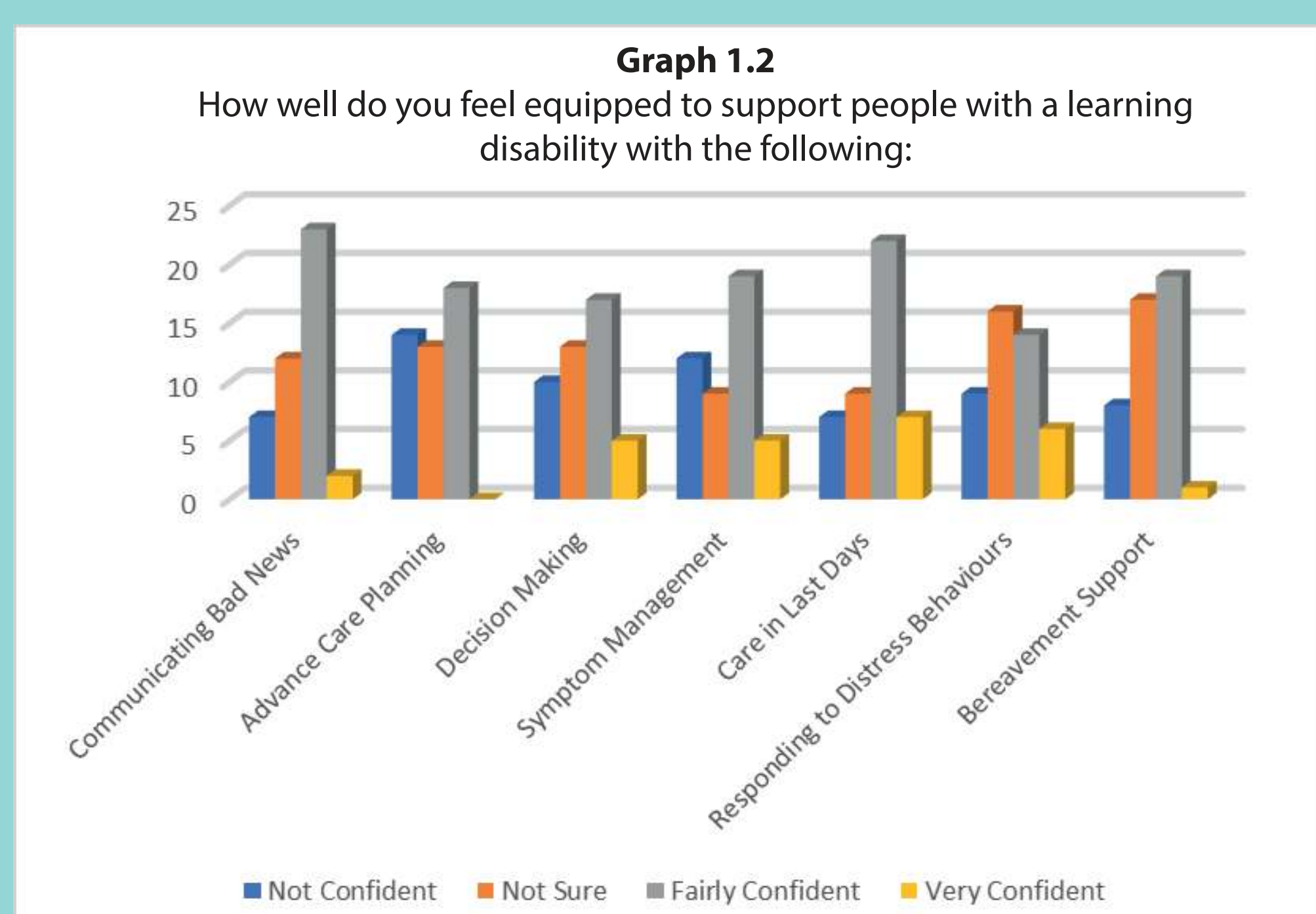
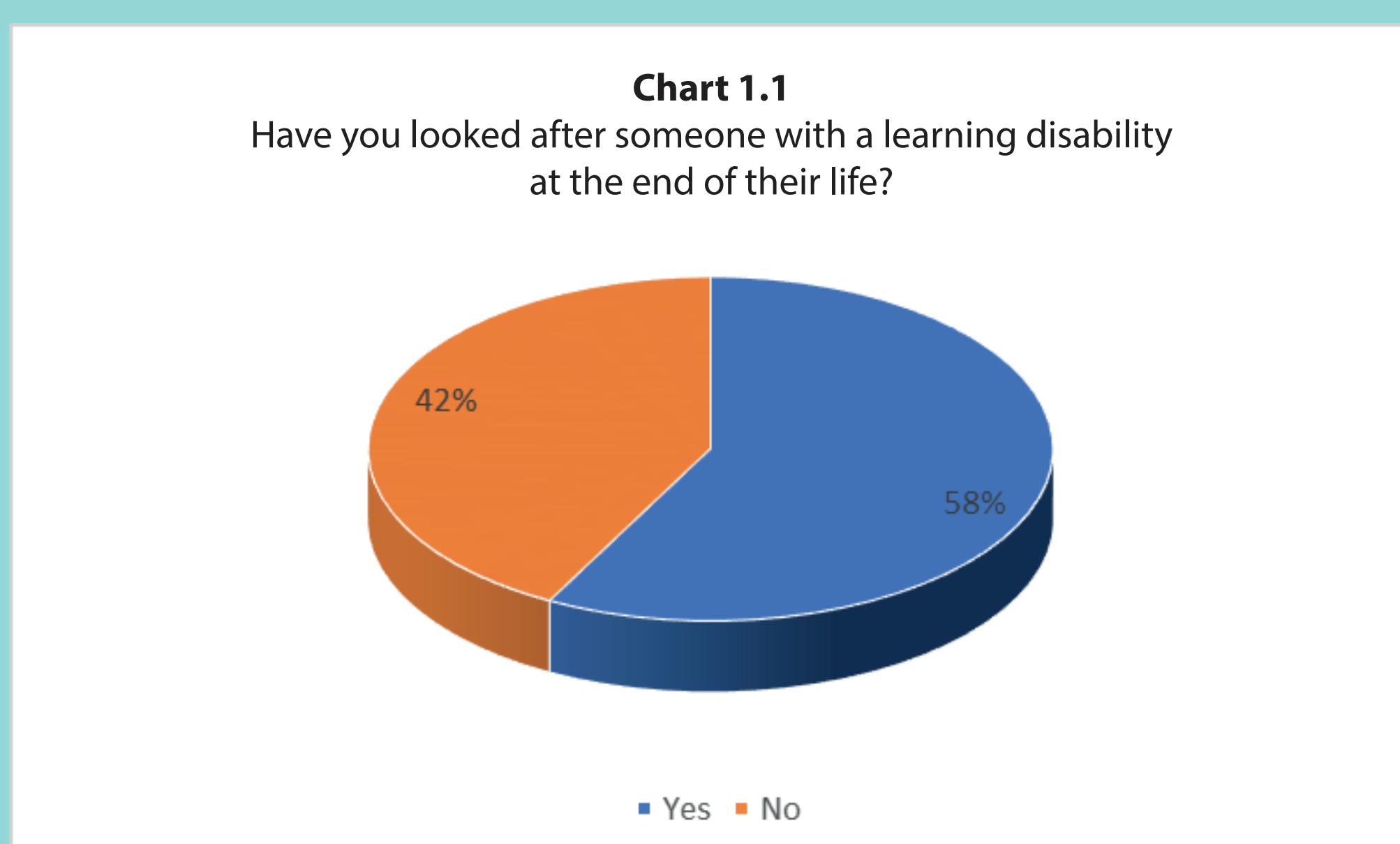
- Raising awareness of the need for SPC interventions for individuals with LD
- Equity of access to good palliative care and Advance Care Planning (ACP) for individuals with LD
- Enhancing knowledge and understanding about what a Learning Disability is and the impact upon care needs



Finding the gaps

An online GAP analysis survey was shared across hospice and LD statutory provision to identify training needs and establish variances in confidence and knowledge about working with people with LD at the end of their lives or as a relative facing bereavement.

Chart 1.1 illustrates the respondent's current experiences of looking after an individual with LD at the end of their life. Graph 1.2 demonstrates the professional's perceived levels of ability in a variety of aspects of EOLC.



Bridging the gaps

The Learning Disability EOLC Facilitator:

- provides tailored support, resources and signposting to ensure the right services are involved to support people with Learning Disabilities who may be in the last year of life or who have a life-limiting condition
- works across all aspects of the hospice and LD provision in St Wilfrid's catchment area to consult with staff, patients and their families
- regularly attends the Community Multidisciplinary Team meetings (MDT) where their range of skills complement the Hospice Team
- provides education for the wider Learning Disability provision and within the Hospice – with the aim to leave a legacy of skill and experience
- works with families and care teams directly to inform and advise on materials to aid discussions around death and dying, how to break bad news, recognising and managing symptoms, and dealing with distress behaviour associated with grief

The GAP Analysis identified key areas for staff teaching, and the decision was made part way through the project to offer these sessions across all Sussex Hospices, and the Sussex Partnership Foundation Trust.

These have included:

- Learning Disability Awareness
- Breaking Bad News
- Distress Behaviours in people with LD, Autism and/or Cognitive Impairment

GP Practices in the hospice catchment area are encouraged during Palliative Care Register meetings, to review their LD registers and consider any patients who would benefit from hospice involvement.



On track for

- A series of community workshops with carers, parents and experts by experience with a Learning Disability.
- To review materials available for ACP discussions and to consider design of accessible alternatives
- Starting those all-important conversations.
- Engaging with children's services, young people and their families, to identify the role of the adult hospice in transition.
- Leaving a legacy of learning and joint working across hospice and Learning Disability Services.
- Inspiring review and development of Specialist LD and Autism roles in EOLC

References

1: Tuffrey-Wijne, I. (2003) The Palliative Care needs of people with intellectual disabilities: a literature review, Palliative Medicine, Vol 17 (Issue 1), 55-62

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