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## Title

Excellence in palliative and end-of-life care provision for people with intellectual disability (ID): content analysis of award winning practice initiatives and care provision in the UK, 2008-2018

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## Abstract

**BACKGROUND:** People with ID experience significant inequalities in end-of-life and palliative care provision.

**AIMS:** To identify the key characteristics of practice initiatives and case reports that have won a UK award for outstanding provision of end-of-life care for people with ID (2008-2018).

**METHODS:** Thematic content analysis of the written nominations for award winners and those highly commended (n=25).

**FINDINGS:** Four themes were identified: (1) Good practice was dependent on 'champions' with drive, enthusiasm and determination, supported by committed organisations and managers. (2) Collaboration was essential, including collaboration with families. (3) Care was highly individualised, putting the person's story at the centre. (4) There was a focus on staff training and use of specifically designed or adapted tools.

**CONCLUSION:** The good practice examples are encouraging. Focus is now needed on ensuring that good practice is sustained, replicated and embedded within policies and organisational cultures. Currently, it remains over-dependent on committed individuals within organisations.

## Key words

Intellectual disabilities; Palliative care; End of life; Healthcare quality, access and evaluation; Delivery of healthcare

## **Introduction**

This paper provides an overview and analysis of practice initiatives that have won a UK award for excellence in palliative and end-of-life care provision for people with ID, given annually by the Palliative Care for People with Learning Disabilities (PCPLD) Network. The PCPLD Network is a UK charity aiming to raise awareness of the palliative care needs of people with ID, to share and promote best practice, and to enhance collaboration (PCPLD Network, 2018). The Linda McEnhill Award is given to individuals, teams, organisations or collaborations that have initiated a new development, project or innovation, or provided outstanding end-of-life care to one person with ID (see box 1).

### **Intellectual disability (ID): definition and prevalence**

According to the World Health Organisation (2018), ID means “a significantly reduced ability to

understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.” ID affects around 2% of the population; this is approximately one million people in England (Learning Disabilities Observatory, 2016). In the UK, the term “learning disability” is often used, rather than ID.

### **Health inequalities**

A large population-based study in Finland found that whilst people with ID had a lower life expectancy, those whose ID was mild had a similar life expectancy to the general population (Patja et al, 2000). More recent UK research has found, however, that life expectancy for all people with ID remains significantly below that of the general population (Emerson, Glover, & Wolstenholme, 2014). The UK Learning Disability Mortality Review Programme found that in 2017, the median age at death was 47 for people with severe and profound disabilities and 63 for those with mild or moderate ID. The most common causes of death were diseases of the respiratory system (31%), circulatory system (16%) or cancers (10%) (Norah Fry Centre for Disability Studies, 2017). The health care inequalities experienced by people with ID have been well documented. Higher mortality rates arise not only from factors associated with ID, including multiple comorbidities, but also from problems with healthcare delivery (Emerson and Hatton, 2013; Glover et al., 2017; Haveman et al., 2011).

### **Barriers to end-of-life and palliative care**

The trend towards increasing longevity means that growing numbers of people with ID are dying of conditions usually associated with older age, which often includes a pre-dying period of ill health and a possible need for palliative care. The problems with healthcare delivery extend into the provision of end-of-life and palliative care. A UK review into inequalities in end-of-life care identified people with ID as being at risk of poorer quality care at the end of life, because their needs are not always fully understood or considered by providers (Care Quality Commission, 2016). An inquiry into the deaths of 249 people with ID found that they were less likely than the general population to have access to specialist palliative care services, and that their deaths were not being planned for, poorly coordinated and poorly managed (Heslop et al., 2013). There is consensus within the literature

about the barriers people with ID face at the end of life. They include the following: difficulties with communication which affect all aspects of palliative care provision, including pain and symptom assessment; difficulties with patient insight into the condition, its treatment and possible outcomes; lack of involvement in end-of-life decision-making; multi-morbidity and polypharmacy; complex social circumstances that may involve families as well as care staff complex social circumstances; lack of reasonable adjustments to care; transitions in care settings; lack of experience among healthcare staff of people with ID; and lack of experience among ID staff of illness, death and dying, leading to fear and avoidance (Cross et al., 2012; Dunkley and Sales, 2014; Friedman et al., 2012; Moro et al., 2017; Read, 2013; Sterling Welch and Moreno-Leguizamon, 2016; Tuffrey-Wijne and McLaughlin, 2015).

### **Palliative care and intellectual disabilities: best practice guidance**

Evidence-based practice is essential for the provision of high-quality palliative and end-of-life care. However, the research evidence base of how best to meet the palliative care needs of people with ID is extremely limited (Tuffrey-Wijne et al., 2016). A White Paper on ID of the European Association of Palliative Care (EAPC) asserts that it is not always easy to apply existing guidelines for good palliative care to people with ID (Tuffrey-Wijne et al., 2015). The EAPC White Paper outlines 13 consensus norms that provide guidance on what good practice looks like. In 2017, the PCPLD Network together with NHS England published a document of 'top tips' for commissioners, service providers and health and social care staff, adapting a national framework (Ambitions for Palliative and End of Life Care, 2015) to the specific needs of people with ID (NHS England and PCPLD Network, 2017). These two guidance documents stipulate that people with ID should have timely and equitable access to palliative care; have their holistic needs recognised, assessed and addressed; be informed and involved in their care and in decision-making; and have their family and carers involved. Services should be proactive, work collaboratively and provide staff training (see Table 1).

### **End-of-life care provision for people with ID in the UK**

There is limited research internationally on where people with ID are cared for at the very end of life or where they die; a literature review found no large-scale studies with regards to this (Moro et al., 2017). A UK mortality review found that 64% of people with ID died in hospital, compared with 47% of hospital deaths in the general population (Norah Fry Centre for Disability Studies, 2017). It is likely that people with ID in the UK spend their final years, months and weeks of life in a wide variety of settings. Almost half of all people with ID in England who receive long-term social care support live with family or friends; almost a quarter live in registered care homes; and almost a quarter in supported living accommodation (Learning Disabilities Observatory, 2016).

Dying at home is often seen as the preferred scenario for people with ID, but whether this is possible needs assessment not only of the suitability of the physical home environment but also of staff skill (Bekkema et al., 2015a, 2015b). The social care staff who support people with ID are typically not trained in healthcare and rarely have experience in end-of-life care provision. They therefore have significant training and support needs in this area (Tuffrey-Wijne 2009; Ryan 2011; Todd, 2013; Tuffrey-Wijne et al., 2017). People with ID living in any setting (including with families) may receive support from Community Learning Disability Teams, which typically include ID nurses and social workers. Northway et al. (2018) found that both community and hospital nurses are involved in

supporting people with ID during the final months of life, who need appropriate education to undertake this role.

For the provision of specialist palliative care, they are dependent on accessing the same services as the general population, such as hospices and community palliative care teams. There is some evidence that such services are under-used by people with ID in the UK, and that palliative care professionals lack knowledge and confidence in supporting people with ID (Cross et al., 2012; Tuffrey-Wijne et al., 2008).

When people with ID use services that are not developed with their specific requirements in mind, they are at risk of being marginalised and of receiving inappropriate care (Kirkendall et al., 2016; Sterling Welch and Moreno-Leguizamon, 2016). The situation in the UK is particularly challenging as a result of health and social care budget cuts which have a direct impact on the lives of people with ID, leading to understaffed, under-resourced and under-prepared teams trying to do their best in difficult circumstances (Sterling Welch and Moreno-Leguizamon, 2016).

### **The Linda McEnhill Award**

The annual Linda McEnhill Award was established in 2008 in order to highlight best practice in the provision of end-of-life and palliative care for people with ID, thus providing a platform for national sharing and learning. During the first years of the award, assessment criteria focused on an expert judgment of excellence, innovation, evaluation and impact. From 2012, further criteria were added to include patient-centred care, management of needs, collaboration, and support for carers. Nominations are scored independently against these criteria by around 6 expert judges, including a nurse, consultant and social worker in palliative care (at least one of whom has both academic and clinical expertise), ID nurses and a family carer. A shortlist of the top scoring nominations is then discussed until consensus is reached at a final judging meeting of 4 or 5 judges, including a palliative care expert, an ID expert, a family carer and one or two people with ID. Replicability, impact and the possibility to inspire others is a particular focus for the final decision (see box 1).

We believe that it is important to examine and report on the details of a decade of award-winning practice, given the dearth of available literature about the characteristics of palliative care service provision for people with ID. We hope that this will highlight the possibilities for excellence and improving practice in a context which, as has been described above, is highly challenging and prone to sub-optimal care provision.

The purpose of this paper, therefore, is to describe the key characteristics of practice initiatives and case reports that have won or were highly commended for the Linda McEnhill Award.

## **Methods**

### **Sample**

A total of 25 people, projects or teams won the Linda McEnhill Award or were 'highly commended' between 2008 and 2018. Thirteen of those had initiated a "new development, project or innovation"

(category A): three cross-organisational projects, two hospices, an ID service provider, an ID support organisation, an ID nurse and five hospice-based palliative care professionals (two social workers, two nurses and a consultant). Their initiatives included the development of cross-professional and cross-organisational collaborative links, developing training or new resources, developing care pathways and ensuring proactive end-of-life support. Twelve teams won the award for providing “outstanding end-of-life care to one individual” (category B): five ID residential care homes or home support teams (one of which won twice), two multi-disciplinary teams (including the family) for an individual in their own home, one pair of ID key workers, one mother together with the person’s dementia nurse, and one cross-organisational group. See a short description of all winners in table 2.

## Procedure

The data for this paper were the full nomination documents submitted to the PCPLD Network (typically around 1,500 words in length). These were analysed using ‘Framework’, a thematic content analysis method (Gale et al., 2013). This is a structured step-by-step method which is particularly suitable for analysing qualitative data on similar topics that can be fairly easily categorized. It can accommodate less experienced researchers, which was useful as only one of the authors is an experienced qualitative academic researcher. The step-wise process was as follows: **(1) Coding:** A summary of 20 winning nominations, published on the PCPLD Network website ([www.pcpld.org](http://www.pcpld.org)), were read by both authors and themes (“codes”) were extracted from these brief descriptions. **(2) Developing the framework:** The lead author grouped the codes into eight categories and developed into an analytical framework. **(3) Applying the framework:** The first 20 full nomination documents were then imported into Nvivo software for qualitative analysis (Bazeley & Jackson, 2013) and the texts were coded using the framework. No further codes needed to be added at this stage. **(4) Charting the data:** The lead author read the codes by category and summarised them within the Nvivo software, using illustrative quotes from the nominations. **(5) Interpretation:** The authors discussed the data, exploring relationships and connections between categories, to arrive at the final four themes and interpretation. **(6)** After the process was completed, two winners and three highly commended awards were announced for 2018 (there was no award in 2017). These were also coded within the framework and discussed, confirming and strengthening the findings.

See table 3 for an overview of all codes (step 1), categories (step 2) and themes (step 5), as well as an example of charted raw data (step 4).

No ethical approvals were needed for this project. Information about the winners is publicly available on the PCPLD Network website, including, in several cases, details about individuals who have died. Permission was obtained from the families to make this information public; most families were insistent that this should include the person’s real name. Where permission was not obtained, names have been changed and personal details obscured.

## Results

Four overlapping themes emerged from these practice examples: 'Individual and organisational commitment', 'Working together in collaboration', 'The person's story is at the heart of care', and 'Developing tools and staff training'. Figure 1 gives an overview of how these themes link together, giving an overview of the features of good practice in delivering high quality end-of-life care to people with ID in the UK.

### 1. Individual and organisational commitment

Significant commitment from individuals and organisations was the source and foundation of good practice. Most projects and initiatives (n=19) were highly dependent on one or more individual 'champions'; these were professionals of any grade or background who spearheaded the work with drive, enthusiasm and determination (see the example for charted data in table 3). The six individual category A winners had initiated and sustained projects that achieved system-wide change. Category B winners managed to provide outstanding care, sometimes against the odds, thanks to staff dedication and commitment.

Organisational commitment came in the form of funding and support for developing policies, giving staff time to develop projects or deliver and attend training. Supportive managers were also important (in several cases, it was the service manager who nominated the winning staff member). The general trend was for individual champions to initiate excellent work, which was then supported by their organisations. One exception was the 2018 winner (St Christopher's Hospice, A13), whose winning project had been initiated and funded by the local commissioner and then taken on and supported by the hospice, with staff rising to the challenge. Conversely, others remained utterly dependent on staff enthusiasm. One team wrote:

*"We have maximised resources (we have had no extra expansion of our staff numbers to develop/deliver [these project initiatives]) but looked really hard at "What can I do?" within our own roles (...) This is the most amazing set of people with a can do attitude, with care and respect for the individual at the core of the care that they deliver, which has taken this forward despite organisational challenges."*

Some initiatives had not yet become established at the time of the award, making it difficult to assess sustainability. Those projects where a wider group of practitioners had been enlisted and committed to the work from the beginning had usually been established for several years, and were more clearly embedded within organisational practice, gaining commitment from funders along the way. An example is A8, a jointly led project in Glasgow, which has gained recognition and support from the Scottish government.

In several cases, winning teams had undergone a comprehensive learning process, enabling good practice to be sustained. Indeed, one residential home won twice, in 2010 and 2015 (Heatherstones, B1 and B9) (Wainwright, 2011). They had become like a 'beacon home', having gained a reputation

for providing excellent end-of-life care and thus receiving a number of referrals for people with ID with palliative care needs. In fact, the ID service provider of which they were part became an overall winner in 2015 (St Anne's Community Services, A10). Following the training of staff in Heatherstones that led to the 2010 award, the organisation had become committed to supporting all their homes, teamed up with the local hospice, adapted generic palliative care assessment tools to suit the needs of people with ID, and convinced the local funding agency to make end-of-life training mandatory for ID care homes. The way in which good practice can grow and inspire was further demonstrated by the 2018 winner (St Christopher's Hospice, A13), who went to visit and learn from St Anne's Community Services before further developing these practices and resources in their own award winning project.

## **2. Working together in collaboration**

Most winning project (n=21) described good collaboration between services. Category A projects included the establishing of networking links, regular interdisciplinary meetings to discuss general issues as well as specific clients, and running workshops. According to one winning nomination,

*"As a group we continue to meet regularly to make sure that strong and continuing relationships exist between those caring for vulnerable adults through serious illness, those who know them from home, and the palliative care team in the hospital. We are much more confident that we understand each other's roles in the care and support of someone with [ID]."*

Category B case reports showed how the contribution of a wide range of professionals enhances holistic care. A mother wrote,

*"Everyone had to learn to work together... Initially the palliative care team were surprised by our experience and expectations! We were relieved when we found they could open doors and had the professional ability to get other medics to follow our protocol."*

Fifteen winners, including almost all category B winners, demonstrated the importance of including families in the collaboration. Care was particularly good where families were able to allow professionals and paid care staff to contribute, respecting their input and expertise, and vice versa. One team member said,

*"She had the most detailed Health Action Plan, Health Passport, Care Plan and finally Advanced Care Plan. These documents were jointly written by her teams and parents and proved invaluable working guidelines... Her family look back now with peace and pride in being part of the team that enabled her to live happily and die majestically."*

## **3. The person's story is at the heart of care**

This theme is central to all others. It means that the person's life story is taken into account, with careful thought given to the person's individual needs and wishes, even if they are unable to express them clearly. Care is thus highly person-centered.

In 16 of the winning nominations, the described care was proactive and well planned, highly individualised and often creative, with responsive and flexible professionals and carers. Symptoms



were carefully assessed with the support of those who knew the person well and those who had expertise in symptom control. End-of-life decisions included careful consideration of the best place of care (which, in all winning nominations, was at home), and an avoidance of unnecessary hospitalisations. Huge efforts were made to overcome the barriers that might prevent people with ID from being cared for at home, for example, through providing training and support for staff and through staff being creative and flexible. All those involved wanted to make sure that the person's voice and wishes were heard, even if the person was unable to express those in words. One hospice team explained,

*“Staff re-visited the person-centred information which had already been gathered to consider its ongoing relevance. For example, what made a good day and bad day for him was changed because of his illness... Information on his likes, interests and what was important to him was also read by hospice staff.”*

#### **4. Developing tools and staff training**

Good practice was supported by the development of resources, tools and pathways; these featured in 18 of the nominations. For example:

*“This collaborative work resulted in the hospice changing its referral forms to ensure that people with vulnerabilities, such as [ID], are highlighted. A Fast Track Pathway was created towards early face to face contact with the client and their key worker.”*

Some organisations found that tools used towards the end of life for the general population were not suitable for people with ID, and developed adapted versions. Staff training featured strongly, both on cross-organisational level and within individual teams and care homes, as in this nomination:

*“She developed training for hospice staff in joint collaboration with the joint [ID] team, the Healthcare Foundation Trust and the service user advocacy group.”*

## **Discussion**

The many and varied good practice examples of palliative and end-of-life care provision of people with ID in the UK are encouraging. They demonstrate a myriad of ways in which the barriers that have been described in the literature can be overcome. In particular, the findings confirm the complexity of issues, the wide range of stakeholders and services involved in each situation, and the importance of interdisciplinary collaboration (Kirkendall, Linton, & Farris, 2016; Sterling Welch & Moreno-Leguizamon, 2016; Tuffrey-Wijne & McLaughlin, 2015)

### **1. Individual and organisational commitment**

Examining the characteristics of good practice initiatives, one of the most striking findings is the extent to which good practice was dependent on individual champions. This might be seen as positive, as it demonstrates the extent to which staff working in health and social care systems can make a real difference. It is interesting to see that system-wide changes can be initiated by

practitioners in any setting. Staff working in ID settings made real changes by expanding their practice to include knowledge and expertise in end-of-life care; similarly, palliative care staff made a huge difference by reaching out to the population of people with ID. Joint championing, where there was enthusiastic commitment across professional boundaries, was particularly successful. The drawback of this reliance on individual practitioners, however, is the possibility that good practice is not sustained when the champions stop championing, either because they leave or because they need to focus their attention elsewhere. Organisational support is therefore particularly important. In the examined good practice examples, such support came primarily in the form of encouraging managers who enabled staff to spend the necessary time on project and supported staff training. This is consistent with the results of a literature review of good health and social care practice in the provision of care for people with ID at the end of life, which found that the full and creative support of senior management is essential for achieving best practice (Sterling Welch and Moreno-Leguizamon, 2016).

This need for managerial support may also impact on sustainability of the award-winning practice initiatives, as they could be curtailed by changes in management. A few award winning projects were underpinned or supported by funding from local authorities. In some cases, local guidelines and policies had been changed, for example, to include mandatory staff training. Sustainability and long-term impact of good practice initiatives have not been properly investigated, but anecdotal evidence (gathered from conversations by the authors with many of the award winners) suggests that it is indeed the case that projects may wither if staff or managers leave. It seems, though, that without national, local and organisational policies, guidelines and funding, a postcode lottery is created as good end-of-life care for people with ID depends on committed individuals and organisations. This issue has also been noted by other researchers; for example, Grindrod and Rumbold (2017) found that in Australia, options for people with ID to receive end-of-life care dependent more upon staff attitudes than on organisational policies, and assert that person-centred care provided by individual staff must be embedded within models and structures of care. The EAPC White Paper on ID (Tuffrey-Wijne and McLaughlin, 2015), which includes an analysis of 88 good practice examples from 13 European countries, similarly found that good practice often depended on the dedication of individual practitioners. They conclude that one of the challenges for the future is to find ways to 'scale up' good practice and ensure that they are embedded within services and systems.

## **2. Working together in collaboration**

Collaborative working has been consistently highlighted in the literature as essential to the provision of good palliative care to people with ID, and as such it was part of the judging criteria. It is therefore not surprising that winning practice almost always included good collaboration between services (n=21). The added value of sharing expertise was striking, with palliative care professionals learning from ID professionals and vice versa.

The need for collaboration between services has been one of the most consistent findings in the literature on end-of-life and palliative care for people with ID (e.g. Dunkley and Sales, 2014; Friedman et al., 2012; Grindrod and Rumbold, 2017; Moro et al., 2017; Tuffrey-Wijne et al., 2015; Tuffrey-Wijne et al., 2007).

There are significant challenges to the establishment of cross-professional partnerships. Cross et al (2012) describe a 3 year project aimed at exploring ways to improve palliative care provision for people with ID in London, involving four hospices and 228 care homes. They found that ID staff and palliative care professionals lacked understanding of each other's role and were unsure of what the other service was providing. Kirkendall et al. (2012) assert that the development of partnerships between palliative care and ID services is challenged by their different philosophies. ID services tend to foster the individual's empowerment, often through supporting the acquisition of life skills; they may need support in translating the philosophy of empowerment into support for people whose health and capabilities are deteriorating. Among all professional groups, there is a lack of recognition of the palliative care phase (Vrijmoeth et al., 2016).

Most category A initiatives aimed to address these challenges by using various strategies including staff training, hospice outreach programmes, inter-professional workshops and regular meetings between palliative care and ID practitioners. Most initiatives used more than one strategy, which seems appropriate given the complexity of the issues to be addressed. The projects had clear benefits for staff, in terms of confidence and readiness to provide palliative and end-of-life support to people with ID. The benefits for people with ID themselves, and for their families, were mostly illustrated through case examples.

Good relationships with families are crucially important. Families are unique in their profound understanding of the person's identity, communication and needs, and often central in the person's life; three quarters of informal carers of people with ID have been caring for over 20 years (Hatton et al., 2014). In several studies, staff working in ID services reported how their relationships with families could become more difficult towards the end of a person's life; they described disagreements about decisions and feeling excluded from the end-of-life process (Ryan et al., 2011; Todd, 2013). Enabling families to care for the person at the end of life required robust support from professionals. Initiatives where staff listened to and worked together with families were therefore particularly encouraging. Often, collaboration with families was a learning curve, and those involved had to do things in a new or different way.

### **3. The person's story is at the heart of care**

The creativity and individual approach needed to address individual patient needs was clear in the descriptions of category B winners. Collaboration can lead to shared learning and to a recognition of those needs of people with ID that could be met by professionals from another specialty. The category A projects indicated that it may be possible to prepare for flexible and individualised ways of working through establishing sustained collaborative links, although it is likely that unique ways of working need to be found for each patient with ID and their families and carers.

Placing the person at the heart of care reflects a patient-centred philosophy that sits well with both ID and palliative care services (Kirkendall et al., 2012). It requires the person, with their likes, dislikes and personality, to be known to those who support them. Previous studies have found that ID staff themselves recognise the importance of this, and their role in ensuring that close relationships can be maintained towards the end of life (McCarron et al., 2010; Ryan 2011; Todd, 2013). People with

ID themselves also place importance on having good relationships with people who are there for them at the end of life (Tuffrey-Wijne, 2010; Bekkema et al., 2016).

Within palliative care services, there is a focus on developing ways in which patients and families be fully involved in advance care planning (ACP) and end-of-life decision making (Houben et al. 2014; Lovel and Yates 2014); this focus is beginning to extend to ID services (Voss et al. 2017). Of interest with regards to ACP is the way in which winning teams ensured that the person's life story took centre stage and was at the heart of careful and ongoing consideration of their needs and wishes. This meant that even the perspectives of people with profound ID could be included in care planning (e.g. B6, B7, B10). It would be worthwhile to investigate further exactly how professionals approached ACP involving people who lacked capacity and who were unable to comprehend their situation. The winning projects suggest that story telling may have an important contribution to make to the ACP process. This is in line with the findings of an Australian study that the involvement of people with severe and profound ID in decisions, including end-of-life decisions, depended on the person being supported by people who had a close relationship with them, and not only knew their life story, but shared it with others (Watson, Wilson, & Hagiliassis, 2017).

Within ID services, there can be a sense that homes are not set up to provide more intensive care needed as residents age. The perceptions of managers on whether it is possible to manage the person's condition are particularly important (Bekkema et al., 2015b; Bigby et al., 2011; Webber et al., 2010). Among the winning good practice examples, there was an emphasis on finding creative ways of enabling the person with ID to be cared for and to die at home. In line with the findings in the literature, this involved flexibility, staff training, leadership and management support.

#### **4. Developing tools and staff training**

The need for staff training is a consistent conclusion within the literature on end-of-life care for people with ID. This includes training for ID staff to address end-of-life needs, and for general healthcare staff (including palliative care staff) to understand and address the needs of people with ID. However, there is limited research on what kind of training is most useful, or indeed on whether training changes practice (Moro et al., 2017). Cross-disciplinary training, as shown in the winning projects, certainly seems valuable and appeared to raise staff confidence, but it would be important to measure outcomes, such as the effect of staff training on care delivery.

Tools and pathways can help, for example, to enable early access to specialist palliative care services and to support the assessment of a person's health status and symptoms. However, as the team working with the Gold Standard Framework found, their use is not straightforward; some tools have been adapted to the needs of people with ID, but even then, they may still need to be adapted to individual circumstances.

#### **Limitations**

The obvious limitation is that the authors of this paper were themselves involved in setting the benchmarks and judging criteria for the Linda McEnhill Award, which affected the outcomes of this analysis. However, these criteria were based on combined expertise of PCPLD Network members as well as the limited empirical knowledge base, including grey literature, and as such are likely to be highly relevant.

The work presented here is further limited by the fact that the nominations containing the project descriptions mostly were written by a professional or manager closely involved with the winning project, constituting staff self-assessment of the project's strengths and weaknesses. As these nominators were hoping to win the award, they were likely to emphasise the positives and gloss over the negatives. In order to achieve a more objective assessment of the initiatives, an independent evaluation would be needed, using externally determined outcome measures. Ideally, these should include the perspectives of families and carers and, wherever possible, of the people with ID themselves.

This paper describes practice in the UK, which sits within a context of dispersed ID services and well-established specialist palliative care services. This limits its international relevance. Clearly, how the necessary expertise is accessed depends on the organisation and availability of services in each country (Tuffrey-Wijne and McLaughlin 2015). However, the principles behind good practice are likely to be of relevance regardless of country or setting.

Few projects used outcome measures to assess the impact on access to palliative care services, for example through referral rates to specialist palliative care services or unplanned hospital admissions. Where such outcomes were described, they were not on a sufficient scale or covering a sufficient time frame to be able to draw conclusions about the project's effect on access to services. The benefits of the project initiatives for the overall population of people with ID (rather than for individual cases) were implied, but not explicitly demonstrated.

## **Conclusion**

It is clear that individual practitioners can make a significant positive difference to the palliative and end-of-life care of people with ID. These practice examples could, and should, be an inspiration for practitioners and services who wish to improve their care provision. They can teach us much that would benefit not only people with ID but indeed the general population, e.g. how care can be planned with people who are non-verbal, and how families can be truly involved as partners in care.

However, good palliative care for people with ID should not be dependent on the fortunate presence of committed professionals with a passion for this area of care, or on being within the catchment area of one of these inspirational projects and services. Nor should it be up to a small charitable organisation like the PCPLD Network to ensure that good practice is promoted and replicated. Within the UK, numerous practice initiatives such as the ones described in this paper are emerging, and there is a danger of different services spending time and resources to invent the same wheel. Without the support of national policies and adequate funding, the postcode lottery is likely to continue, as is the danger that good initiatives are not sustained when staff leave.

There need to be policies and requirements at national level to meet key performance indicators around the provision of reasonably adjusted care for patients with ID at the end of life. In order to support the development of such policies, data are needed about the cost and benefits of practice initiatives, as well as investigations of what works where, for whom, and under what circumstances.

It is also crucially important to investigate sustainability of good practice initiatives. This warrants robust research with relevant outcome measures, such as patient and family satisfaction, quality of life, evaluation of pain and other symptoms, evidence of advance care planning (including patient involvement in this), achievement of preferred place of care and preferred place of death, referral rates to specialist palliative care services, rates of unplanned hospital admissions, and any additional staff time needed. There is still little known about the transferability of outcome measures used within palliative care for the general population to a population of people with ID; this, too, needs investigation.

Finally, we note the limited involvement of people with ID themselves in developing good practice. People with ID and families need to be more involved in the development of tools, resources, training and policies.

## **Key points**

- Providing palliative and end-of-life care for people with ID is challenging, but there is a limited research evidence base of how their needs can be best met.
- This project looked at the features of 25 best practice initiatives that have won a UK award for best practice in palliative and end-of-life care provision for people with ID. It shows that it is important to work together in collaboration, and to put the person's story at the heart of care.
- Individual and organisational commitment was key to good practice. Good practice is not currently embedded within policies and organisational structures, and is therefore vulnerable to being discontinued when committed staff leave.
- There is a need for national policies and key performance indicators to ensure that the palliative care needs of people with ID are met.
- There is a need for robust research about what works where, for whom, and under what circumstances.

## **Continuing professional development: reflective questions**

- Have you ever cared for a patient who had ID? If so, what were the challenges?
- How confident do you feel in providing care for someone with ID? What would be your main worries or concerns?
- What steps could you take to improve your knowledge and competence in providing palliative care for people with ID? Who could provide training for you and your colleagues?
- Who should be involved in supporting people with ID in your setting? What steps could you take to ensure effective collaboration?
- Has your organisation taken any steps to ensure that people with ID are not disadvantaged when using your service?

## Box 1: The Linda McEnhill Award

The Palliative Care for People with Learning Disabilities (PCPLD) Network, founded in the UK in 1998, has brought practitioners together to share best practice. In 2008, the PCPLD network introduced an annual award (the 'Linda McEnhill Award') for outstanding practice in the provision of end of life care support for people with intellectual disabilities. It is awarded to individuals or teams that have made a positive difference to the palliative and end of life care for people with intellectual disabilities. In 2011, two categories were introduced, with the potential to have one winner in each category:

**(A)** A new development or innovation in care, or excellence in overall end of life support for people with intellectual disabilities (this could be, for example, a clinical development, an educational project, a piece of research, or anything else that will benefit a number of people with intellectual disabilities).

**(B)** Outstanding end of life support of an individual with intellectual disabilities.

Anyone can nominate a team or individuals for the award; self-nominations are also accepted. The judging panel includes clinicians in the fields of both intellectual disabilities and palliative care, two people with learning disabilities and a family carer. It is chaired by Irene Tuffrey-Wijne, a pioneering researcher in the area of palliative care for people with intellectual disabilities and founder member of the PCPLD Network.

Judging criteria are based on what is known about best practice, derived from existing literature and the combined expertise of the judging panel. Category A nominations must demonstrate excellence, innovation in care, evaluation and evidence of impact. Category B nominations must demonstrate patient-centred care, good management of all needs (including physical, social, emotional, spiritual), collaboration with relevant services or people, and support for carers and agencies involved.

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## **Table 1: National and international norms and guidelines for palliative care of people with intellectual disabilities**

### **Summary of the EAPC consensus norms for palliative care of people with intellectual disabilities in Europe (Tuffrey-Wijne and McLaughlin 2015)**

#### **People with intellectual disabilities should have:**

1. Equity of access to palliative care services
2. Understanding of and support for their communication needs
3. Recognition by health and social care providers of when the need for palliative care arises, prompting a person-centred plan for palliative care support
4. Assessment of physical, emotional, social and spiritual needs
5. Recognition, assessment and management of pain and other symptoms; this should include collaboration between those who know the person well and those who are experts in symptom management
6. All necessary support, including advocacy, to enable involvement in end of life decision making; and a recognition of the value of their life and their right to life
7. Involvement of those who matter: families, friends and carers
8. Services that collaborate with all others service involved, and share expertise
9. Support for families and carers, including post-bereavement support
10. Opportunities to prepare for death
11. Bereavement support, including a recognition of a higher risk of complicated grief

#### **Service providers should:**

12. Provide staff education and training; and death education for people with intellectual disabilities
13. Prioritise equitable palliative care for people with intellectual disabilities, including forward planning and providing adequate resources

### **Summary of NHS England/PCPLD Network Guide on delivering high quality end of life care for people with intellectual disabilities in England and Wales (NHS England and PCPLD Network 2017)**

- 1. Each person is seen as an individual**, including:
  - Involving families/friends/carers
  - Support the person's involvement in advance care planning
- 2. Each person gets fair access to care**, including:
  - Allocation of resources
  - Early identification of people with intellectual disabilities reaching the last year of life
  - Make reasonable adjustments
- 3. Maximise comfort and wellbeing**, including:

- Help the person understand their illness and symptoms
  - Effective and appropriate assessment of pain and distress
  - Be creative in relieving psychological distress and improving wellbeing
- 4. Care is coordinated**, including:
- Involving families/friends/carers as partners in care
  - Record the person's preferences
  - Coordinate involvement of staff from different organisations
- 5. All staff are prepared to care**, including:
- Cross-sector training
  - Staff ability to adapt communication skills
- 6. Each community is prepared to help**, including:
- Ensure people with intellectual disabilities are part of the local community
  - Encourage discussion about death and dying with everyone
  - Involve charities and voluntary sector

**Table 2: Linda McEnhill Award Winners (incl Highly Commended)  
2008-2018**

	Year	Name/team	Description of project/practice
<b>Category A: New developments, projects, innovations in care</b>			
<b>A1</b>	2008	Linda McEnhill (palliative care social worker) PCPLD Network, UK	Founding the PCPLD Network (then the National Network for Palliative Care of People with Learning Disabilities) in 1998; chair for 10 years
<b>A2</b>	2009	<b>Saint Francis Hospice</b> <i>Romford, England</i>	Project to improve care for people with learning disabilities within catchment area, including a range of initiatives (collaboration with local learning disability services; changes in the hospice referral form to alert staff to the presence of learning disabilities; fast-tracking patients with learning disabilities; making resource packs and communication tools available to staff; compulsory staff training; identifying among hospice staff 'champions' for adults with learning disabilities)
<b>A3</b>	2009	Lorraine Youdle (team manager) Teighbridge Learning Disability Team <i>Devon, England</i>	Development of an End of Life Checklist Tool, piloted and used by intellectual disability nurses throughout the county.
<b>A4</b>	2010	Jason Davidson (palliative care social worker) St Joseph's Hospice, <i>London, England</i>	Establishing links between the hospice and intellectual disability services in the area; introducing training for hospice staff; making a significant contribution to high quality care provision of patient with learning disabilities referred to the hospice; attracting funding for the hospice to support a project concerned specifically with improving the experience of people with intellectual disabilities at the end of life.
<b>A5</b>	2010	Denise Heals (practice development nurse) Dorothy House Hospice <i>Wiltshire, England</i>	Establishing a two day training programme for direct care staff in intellectual disabilities; supporting practitioners within their own working environment; and helping teams and managers in intellectual disability services to identify training needs and practice development initiatives.
<b>A6</b>	2011	Sharon Hicks (staff nurse) Severn Hospice <i>Shropshire, England</i>	Development of a project called 'Widening Access to Severn Hospice for people with a Learning Disability', which involved a partnership between the hospice, people with intellectual disabilities, carers, the Primary Care Trust and Independent Sector Services. Included developing policies, pathways and easy-read materials.
<b>A7</b>	2012	Ruth Brown (palliative care consultant) and team The Isbister Centre <i>Hertfordshire, England</i>	Setting up the West Hertfordshire Palliative Care Multi Disciplinary Team Referrals Group. Monthly meetings between nurses and social workers from the community intellectual disability teams, and palliative care specialists, to discuss service users who are known to be at the end of life or suspected to die within a year. Development of end of life planning folders to be offered to people with intellectual disabilities across the county.
<b>A8</b>	2013	Liz Smith & Allison O'Donnell (project Leads) Prince & Princess of Wales Hospice <i>Glasgow, Scotland</i>	Project led jointly by practitioners from palliative care and intellectual disability services. Scoping exercise; joint workshops; identification of key practitioners across both disciplines who meet regularly; development of a care pathway. Project supported by Scottish Government and included in national guidance.
<b>A9</b>	2014	PAMIS Bereavement and Loss Project <i>Dundee, Scotland</i>	PAMIS' Bereavement and Loss Project Team developed and published the Bereavement and Loss Learning Resource Pack, focusing on the support of bereaved people with profound intellectual disabilities, and on the experiences and support needs of bereaved parents.
<b>A10</b>	2015	St Anne's Community Service <i>West Yorkshire, England</i>	A service provider supporting people with intellectual disabilities in a range of home settings. Teamed up with local hospice to set up mutual teaching sessions, develop a non-verbal pain tool, put their nursing home teams through Gold Standard Framework training and accreditation, adapted GSF assessment tools to work for people with intellectual

			disabilities, and developed a training package which was made mandatory by the local funding body.
<b>A11</b>	2018	Sunderland Community Specialist Palliative Care Team, Sunderland Learning Disability Community Treatment Team and Sunderland People First <i>Tyne and Wear, England</i>	Collaborative partnership between services over several years. Development of care pathway. Teaming up with local advocacy group to produce easy-read information about palliative care.
<b>A12</b>	2018	Centre 404 and Gentle Dusk <i>London, England</i>	An intellectual disability service provider and an organisation that provides training in 'planning for the last years of life' teamed up to enable conversations about death and advance care planning, producing a support package included staff training, policy, tools and resources, support for families and carers, and awareness raising activities.
<b>A13</b>	2018	St Christopher's Learning Disability Care Home Project Team <i>London, England</i>	Hospice-based project funded by local commissioners. Development of a comprehensive evidence-based programme delivered to 60 intellectual disability care homes within one London borough, aimed at improving access to timely healthcare treatment, appropriate interventions and palliative care. Development of intellectual disability-specific assessment tools and resources, workshops, staff training and intensive support provided by project nurses to the care home teams
<b>Category B: End-of-life support for an individual</b>			
<b>B1</b>	2010	Heatherstones Nursing Home <i>West Yorkshire, England</i>	A nursing home for adults with intellectual disabilities. Outstanding end of life support for a resident with Down syndrome and dementia. The team completed the comprehensive Gold Standard Framework training programme and have maintained GSF accreditation through annual re-assessments.
<b>B2</b>	2011	<b>Hft Falstaff House</b> Warwickshire, England	Residential care home. Outstanding end of life support for a resident who developed dementia.
<b>B3</b>	2012	Janice Byford (mother) and Wendy Broom (clinical nurse specialist for older people with intellectual disabilities) <i>Cornwall, England</i>	Outstanding end of life care for Mrs Byford's daughter, who had dementia and was enabled to die at home. Exemplary collaboration between professionals and family.
<b>B4</b>	2012	<b>Dove House Hospice, Hull City Council, North East Yorkshire and Humber Clinical Alliance</b> <i>East Yorkshire, England</i>	Effective partnership working, shared learning and a commitment to person-centred care leading to outstanding end of life care of a person with intellectual disabilities living in a residential care home, followed by a reflective practice initiative involving a number of agencies and organisations.
<b>B5</b>	2013	Key Housing <i>Glasgow, Scotland</i>	A team providing 24 hour support at home for adults with intellectual disabilities. Outstanding end of life support for a resident, involving a wide range of outside professionals.
<b>B6</b>	2014	Victoria Willson's Team: Jean Willson (mother) and family; Centre 404 Housing Service, Islington ELIPSe, Camden Palliative Care Team <i>London, England</i>	Outstanding end of life support for Victoria Willson, who had profound intellectual disabilities and was supported to die in her own flat by a multidisciplinary team, paid care staff and her family.
<b>B7</b>	2014	Barry McNally and Staff Team at The Conifers <i>North Yorkshire, England</i>	Staff team supporting a man with severe intellectual disabilities and autism, whose behaviour had been challenging for staff. Outstanding end of life support was achieved despite difficult and challenging circumstances.
<b>B8</b>	2015	8 Oxfield Court <i>West Yorkshire, England</i>	Staff team within St Anne's Community Services ( <i>see above</i> ). Outstanding end of life support for a resident

<b>B9</b>	2015	Heatherstones Nursing Home <i>West Yorkshire, England</i>	Staff team within St Anne's Community Services ( <i>see above</i> ). Outstanding end of life support for a resident. (NB This team also won the 2010 award).
<b>B10</b>	2016	Sarah Jane Price's Team Louise Ellis (foster mother) and family; multidisciplinary team <i>Gloucestershire, England</i>	Outstanding end of life support for Sarah Jane Price, a young woman with profound intellectual disabilities, and for her foster family, enabling her to die at home. Hospital palliative care team developed a new care pathway. Excellent collaboration within multidisciplinary team.
<b>B11</b>	2018	Matthew Picton's team: Lorna Campion and Paul Stenhouse (key workers) <i>Worcestershire, England</i>	Key workers provided outstanding end of life support for Matthew Picton, who lived in his own home and was enabled to live a full and active life despite his multiple disabilities and poor health.
<b>B13</b>	2018	Dyke Road Staff Team, Care Management Group <i>East Sussex, England</i>	Outstanding end-of-life support of a woman with profound and multiple disabilities living in a residential care home, and for her family. Excellent management support for the staff team.



**Table 3: Themes, categories and codes**

<b>Theme 1 Individual and organisational commitment</b>	<b>Theme 2 Working together in collaboration</b>	<b>Theme 3 The person’s story is at the heart of care</b>	<b>Theme 4 Developing tools and staff training</b>
<p><i>Champions*</i></p> <ul style="list-style-type: none"> <li>• Leadership</li> <li>• Charisma</li> <li>• Enthusiasm</li> <li>• Going beyond the call of duty</li> </ul> <p><i>Organisational commitment</i></p> <ul style="list-style-type: none"> <li>• Funding</li> <li>• Policies</li> </ul>	<p><i>Collaboration</i></p> <ul style="list-style-type: none"> <li>• Collaboration between LD and PC</li> <li>• Collaboration with people with LD</li> <li>• Working groups</li> <li>• Regular meetings</li> <li>• Mutual learning</li> <li>• <i>(Collaboration with carers/families: currently in the “Families” node)</i></li> </ul> <p><i>Involving the right professionals</i></p> <ul style="list-style-type: none"> <li>• Readiness to care</li> <li>• Available 24/7</li> <li>• Continuity of care</li> <li>• Excellent symptom control</li> </ul>	<p><i>Highly individualised care</i></p> <ul style="list-style-type: none"> <li>• Enabling person to live fully until death</li> <li>• Staff “can-do” attitude</li> <li>• Professionals are open to being challenged</li> <li>• Love</li> </ul> <p><i>Involving families</i></p> <ul style="list-style-type: none"> <li>• Collaborating with families</li> <li>• Supporting families</li> </ul>	<p><i>Training</i></p> <ul style="list-style-type: none"> <li>• Inter-professional</li> <li>• Regular</li> <li>• Compulsory</li> <li>• Conferences / one-of events</li> <li>• Gold Standard Framework</li> </ul> <p><i>Tools and pathways</i></p> <ul style="list-style-type: none"> <li>• Developing new resources</li> <li>• Early referrals</li> <li>• Advance care planning</li> <li>• Adapting from mainstream</li> </ul>

**\*Example of charted data for the category “Champions” (selection)**

**Category A (New developments, project, innovations in care)**

- “Her drive, commitment and determination has given us all more confidence.”
- “His unerring commitment and vision for improving care (...) is inspirational.”
- “Her enthusiasm and passion is infectious.”
- “She has worked tirelessly (...) Amazing (...) Very driven.
- “They approached the development opportunity with enthusiasm and commitment.”
- “The team have been driven and committed.”

**Category B (Outstanding care of an individual)**

- “He was a rock.”
- “The team wanted to look after her.”
- “The team showed courage, determination and loyalty.”
- “Beyond the call of duty.”
- “Staff went to see her often in their home time.”
- “I couldn’t tell who was working and who wasn’t.”

**Figure 1**

The features of good practice in end of life care delivery to people with intellectual disability in the UK

