Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: A mixed methods study
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What is This?
What is already known about the topic?

- A lack of access to good quality palliative care for people with intellectual disabilities is highlighted in the international literature.
- There is evidence that professionals in both intellectual disability and specialist palliative care services lack knowledge, skills and confidence in end-of-life care for people with intellectual disabilities.
- The literature consistently suggests that better partnership practice between intellectual disability and specialist palliative care services is essential to ensure this population are not dying disadvantaged deaths.

Keywords

Partnership practice, intellectual disability, palliative care, questionnaires, interview
What this article adds?
• New insights are provided into partnership practice between specialist palliative care and intellectual disability services.
• Key challenges around the partnership are identified, but the study suggests ways to overcome them and provides examples of how partnership can be actioned.
• A best practice framework for partnership between these services has been developed which illustrates these new insights and could have international applicability.

Implications for practice, theory or policy?
• The framework for partnership practice between the two services could be used to guide service developments such as improved education of service staff.
• The framework should be further explored with services involved in end-of-life care with other patient populations.

Background
Internationally, studies have found that in end-of-life care for people with intellectual disabilities, professionals in palliative care and intellectual disability services have a lack of knowledge, skills and confidence.1–6 Concerns have also been expressed about the quality of palliative care offered to this population.7,8 Yet the World Health Organization9 recognises disability as a global issue with palliative care identified as an international human right.10

A strong theme in the literature is that better collaboration between intellectual disability and specialist palliative care services is essential to ensure that people with intellectual disabilities receive quality end-of-life care and are not dying disadvantaged deaths.2,4,11–14 A lack of referrals of people with intellectual disability to specialist palliative care and hospice services3,6,14 suggests that collaboration and partnership practice between both services is limited. Yet similarities and complementarity between the two specialties have been recognised, but research is needed to understand the style and content of collaborative working between them.6,11,15

Internationally collaborative practice has been emphasised, but requires interdisciplinary education to be effective.16 A growing body of research has explored the conceptual basis for collaboration and its key attributes of ‘sharing’, ‘working together’, ‘role awareness’ and ‘support’17 along with ‘interdependence’ and ‘trust’.18 These attributes are reflected in a conceptual model for partnership practice between health sectors, to impact on inequalities in health, developed by Boydell et al.19 The model depicts a possible pathway of partnership practice, based on connecting, learning, actions, impacts and barriers relating to joint working that could further inform collaborative working in palliative care.19 The European paper on norms and standards for palliative care makes it a requirement for specialist palliative care teams to collaborate with services across all settings.20

Aim
This study aimed to develop a best practice model which would guide and promote partnership practice between specialist palliative care and intellectual disability services.

Methods
Ethical approval was obtained from the University Ethics Committee and Office for Research Ethics Committees in Northern Ireland- Reference Number (09/NIR/03/38).

Research design
A sequential, mixed methods research design involving two phases was used. The first phase focused on services and the second phase on the role of professionals in end-of-life care for people with intellectual disabilities. The study was underpinned by the conceptual model for partnership practice between services.19 However, it was anticipated that the data generated from this study would further inform and develop this conceptual model. Data collection for Phases 1 and 2 occurred between July 2009 and September 2010.

Participants
In Phase 1, a total sample of 66 services, in one region of the United Kingdom, was invited to take part in a scoping study of end-of-life service provision to people with intellectual disability. This included intellectual disability services (n=18), specialist palliative care services (n=28) and nursing homes designated to care for people with intellectual disabilities (n=20).

In Phase 2, a purposive sample was recruited of 30 health and social care professionals, from a variety of disciplines, working in intellectual disability and palliative care services in primary and secondary care, who had provided end-of-life care to adults with intellectual disabilities. Semi-structured interviews were undertaken.

Data collection in phase 1
A key informant was identified for each service in Phase 1. They were forwarded a questionnaire which could be self-completed and returned by post, electronically via a hyperlink or the key informant could request that they
were telephoned to complete their response. Consent was implied through any of these responses. A reminder email was sent followed by a telephone call to non-respondents.

The content of the questionnaire was informed by the literature and focused on end-of-life care and partnership practice between the two services. It consisted of eight quantitative questions, additional comments and four open qualitative questions (copy available from first author (D.M.)). Content validity was assessed by sending the questionnaire to an expert group and piloting it with three services.

Data collection in phase 2

The first author attended team meetings in a range of services to inform professionals verbally about the study and distribute information packs. In all, 30 persons signed and returned the consent forms and semi-structured interviews in their workplace were then arranged. The Consolidated Criteria for Reporting Qualitative Studies (COREQ checklist) was adhered to for this phase of the study.21

An interview guide, adapted from a previous study,2 was used consisting of open questions and prompts to explore services’ experience and perceptions of partnership practice. Participants were asked to reflect on a case scenario of a person with intellectual disability to whom they had provided end-of-life care. The interviews lasted between 40 and 60 min and with participants’ permission were audio-recorded. Field notes were made. The interviews took place in participants’ clinical settings, within a private dedicated area. By the 30th interview, no new themes were emerging so no further recruitment took place.

Analysis of data

Qualitative data obtained from open questions in Phase 1, and interviews in Phase 2, were individually transcribed and content analysed by D.Mc.L. using a recognised framework.22 Transcripts were also independently analysed by two other members of the team (O.B. and S.Mc.I.) and agreement on themes reached through discussion. The main quantitative data collected in the Phase 1 questionnaire were analysed using SPSS (v.11.5) to obtain descriptive statistics. Integration of data from the two phases occurred at the interpretation stage.

Results

Phase 1

In all, 47 services of the 66 services approached (71.2%) responded, including intellectual disability services (n = 10: 56% response), specialist palliative care services (n = 22: 79% response) and nursing homes designated for people with intellectual disability (n = 15: 75% response).

Partnership working between intellectual disability and specialist palliative care services. Only eight intellectual disability services and five nursing homes reported previous contact with specialist palliative care for advice. Likewise half (n = 14) of specialist palliative care services reported contact with their local intellectual disability service for advice.

A varied degree of partnership and joint working was reported (Table 1) with only a minority of services stating that they nearly always worked in partnership with specialist palliative care professionals. By contrast half of nursing homes had never taken part in joint working with a specialist palliative care team. It was noted that two intellectual disability services and four nursing homes had not provided palliative and end-of-life care to adults with intellectual disabilities for joint working to occur.

A positive experience of partnership practice was reported by specialist palliative care services, but highlighted was the limited referrals to their services which precluded relationships being formed with intellectual disability services. More interdisciplinary joint working was thought needed beyond nurse-to-nurse contact.

The main driver for partnership practice identified by services was enabling the person to stay and die in their place of residence. Services were asked to rate on a 5-point scale from very helpful to very unhelpful strategies to promote partnership working between intellectual disability and specialist palliative care services (Table 2). Most services viewed these initiatives in a positive light with no significant difference by type of service.

Around half of the services had provided education and training in this area: 7 intellectual disability services, 9 specialist palliative care services and 10 nursing homes.23

Table 1. ‘Generally how much do you feel your service or team has worked in partnership with specialist palliative care/intellectual disability services in providing palliative and end-of-life care to adults with intellectual disabilities?’.

<table>
<thead>
<tr>
<th></th>
<th>Learning disability services</th>
<th>Nursing homes</th>
<th>Specialist palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>7 (46.6%)</td>
<td>4 (18.1%)</td>
<td>1 (45%)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>3 (30.0%)</td>
<td>4 (26.6%)</td>
<td>8 (36.3%)</td>
</tr>
<tr>
<td>Mostly</td>
<td>2 (20.0%)</td>
<td>2 (13.3%)</td>
<td>1 (4.5%)</td>
</tr>
<tr>
<td>Nearly always</td>
<td>3 (30.0%)</td>
<td>8 (36.3%)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>10 (100.0%) (2 services did not complete)</td>
<td>15 (100.0%) (2 services did not complete)</td>
<td>22 (100.0%) (1 service did not complete)</td>
</tr>
</tbody>
</table>
Nonetheless, all three types of services reported that they could either very adequately or adequately assess and meet the palliative care physical needs of people with intellectual disability and the dynamics of the family or those who matter to the person. However, other domains of holistic assessment and care such as spiritual and emotional needs were found more difficult by around half of services.

Services recognised the value and benefits of joint working and learning in the assessment and care process. This included working with people who had prior knowledge of the person such as professionals or family carers. This made easier assessing and meeting the holistic end-of-life care needs of someone with an intellectual disability.

However, partnership practice between specialist palliative care and intellectual disability services was an identified learning need. Other learning needs relevant to joint working and learning were as follows: communication and assessment/symptom assessment and management, carer support and bereavement care, decision making, understanding intellectual disability and coping with death and self-care.

**Phase 2**

Of the 30 professionals interviewed, 15 worked in intellectual disability services and 15 in specialist palliative care. Participants were representative of disciplines across the multi-disciplinary team within hospital, hospice and community settings; their ages ranged from 30 to 59 years; 22 were female and 8 were male. All had experience of caring for a person with an intellectual disability at the end of life.

The overall theme to emerge from analysis of the transcripts was ‘Effectively meeting the palliative and end-of-life care needs of people with intellectual disabilities’.

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**Table 2. The percentage of services rating the helpfulness of each strategy to promote partnership working between intellectual disability and specialist palliative care services.**

<table>
<thead>
<tr>
<th></th>
<th>Very helpful</th>
<th>Helpful</th>
<th>Neither helpful nor unhelpful</th>
<th>Unhelpful</th>
<th>Very unhelpful</th>
<th>Total response from services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased focus on training on intellectual disability at end-of-life</td>
<td>30 (63.8%)</td>
<td>17 (36.1%)</td>
<td></td>
<td></td>
<td></td>
<td>47 (100.0%)</td>
</tr>
<tr>
<td>Willingness within services to learn from each other</td>
<td>30 (63.8%)</td>
<td>17 (36.1%)</td>
<td></td>
<td></td>
<td></td>
<td>47 (100.0%)</td>
</tr>
<tr>
<td>Joint education with both services on palliative and end-of-life care for people with intellectual disabilities</td>
<td>29 (61.7%)</td>
<td>18 (38.2%)</td>
<td></td>
<td></td>
<td></td>
<td>47 (100.0%)</td>
</tr>
<tr>
<td>Recognising when the need arises for expertise from both services</td>
<td>28 (59.5%)</td>
<td>19 (40.4%)</td>
<td></td>
<td></td>
<td></td>
<td>47 (100.0%)</td>
</tr>
<tr>
<td>Clearer evidence-based guidelines on palliative and end-of-life care for people with intellectual disabilities</td>
<td>27 (57.4%)</td>
<td>18 (38.2%)</td>
<td></td>
<td></td>
<td></td>
<td>45 (95.7%) (2 not completed)</td>
</tr>
<tr>
<td>More funding for cross service support</td>
<td>27 (57.4%)</td>
<td>13 (27.6%)</td>
<td>6 (12.7%)</td>
<td></td>
<td></td>
<td>46 (97.8%) (1 not completed)</td>
</tr>
<tr>
<td>More detailed referral systems to palliative care services outlining specific needs of person with intellectual disability</td>
<td>26 (55.3%)</td>
<td>18 (38.2%)</td>
<td>3 (6.3%)</td>
<td></td>
<td></td>
<td>47 (100.0%)</td>
</tr>
<tr>
<td>Early identification of need by generalist/primary care services to facilitate timely specialist referral</td>
<td>25 (53.1%)</td>
<td>21 (44.6%)</td>
<td></td>
<td></td>
<td></td>
<td>46 (97.8%) (1 not completed)</td>
</tr>
<tr>
<td>More focus on palliative care/intellectual disability in undergraduate training</td>
<td>24 (51.0%)</td>
<td>20 (42.5%)</td>
<td>3 (6.3%)</td>
<td></td>
<td></td>
<td>47 (100.0%)</td>
</tr>
<tr>
<td>Understanding of ethos, philosophy and professional roles in both services</td>
<td>21 (44.6%)</td>
<td>23 (48.9%)</td>
<td>3 (6.3%)</td>
<td></td>
<td></td>
<td>47 (100.0%)</td>
</tr>
<tr>
<td>Regular multi-disciplinary meetings involving professionals across services/sectors to facilitate co-ordinated care</td>
<td>21 (44.6%)</td>
<td>21 (44.6%)</td>
<td>4 (8.5%)</td>
<td>1 (2.1%)</td>
<td></td>
<td>47 (100.0%)</td>
</tr>
<tr>
<td>Clinical placement exchanges between services</td>
<td>15 (31.9%)</td>
<td>22 (46.8%)</td>
<td>9 (19.1%)</td>
<td>1 (2.1%)</td>
<td></td>
<td>47 (100.0%)</td>
</tr>
</tbody>
</table>
This was underpinned by four themes: ‘challenges and issues in end-of-life care’, ‘sharing and learning’, ‘supporting and empowering’ and ‘partnership in practice’.

**Challenges and issues in end-of-life care**

Three sub-categories were linked with this theme: ‘a marginalised life’, ‘equity of access to service provision’ and ‘better co-ordination and continuity of care’.

**A marginalised life.** A marginalised life reflected how services may not have been tailored for people with intellectual disabilities or their needs were often not understood:

When our clients are well at the best of times they present lots of challenges about access to services and about co-operation and stuff … (P2 – Intellectual Disability Service)

**Equity of access to service provision.** People with intellectual disabilities had the right to an equitable service at the end of their life. This included widening access to hospice care:

I think … it is about equity – in that this is a population who is very vulnerable – and it is about … the valuing of human beings and it’s about humanity. (P3 – Specialist Palliative Care Service)

Our contact really with Hospices have been quite limited … in my experience because there’s not a lot of our clients ever manage to get into Hospice service. (P2 – Intellectual Disability Service)

**Better co-ordination and continuity of care.** A number of service improvement areas were highlighted such as more co-ordinated care, with better communication:

I felt quite scared because I wasn’t clear of my role and the whole process was disjointed, un-co-ordinated … what would be helpful is a lead person to co-ordinate palliative care services and if all the relevant professionals were then invited to a case discussion and there was a clear plan and pathway. (P16 – Intellectual Disability Service)

More information about the person’s history … we would sometimes get limited information and learning disability – it’s like an umbrella term. (P9 – Specialist Palliative Care Service)

Other comments related to continuity of care in having people involved who were familiar to and with the person with an intellectual disability:

The thing which made the huge difference was having people who had known her in her other life coming to the hospice and explaining that she liked and needed her dolls … and once the nurses were able to see that then they were empowered to continue to nurse her. (P1 – Specialist Palliative Care Service)

Other participants from a learning disability hospital highlighted why it was important for the person to die in their familiar place of care:

That eye contact was there for forty years … people who had worked with him and that he knew … yes it was a hospital, but it had been his home all of this life. (P14 – Intellectual Disability Service)

**Sharing and learning**

There were a range of educational and training needs within specialist palliative care and intellectual disability services, and informants identified modes of shared learning and working to meet these needs. Highlighted were exchange placements between services, joint liaison working and having intellectual disability/palliative care content in specialist palliative care courses.

**Learning needs in palliative care services.** This included ‘understanding learning disability’, knowing where and how to access local intellectual disability services and issues around communication and assessment:

I would identify it as an area we do need, as a team, more education, in assessment, communication, ethical issues. (P22 – Specialist Palliative Care Service)

**Learning needs in intellectual disability services.** In particular, this is knowing about pain and symptom management, conditions in end-of-life care, bereavement care and caring for people with cultural differences. Other learning needs were self-care in coping with death and dealing with professional grief:

The patients in our care have been here for a considerable length of time, … and staff are nursing them 37½ hours a week for maybe 20 years and you still have that barrier that you’re a professional, but staff do get very extremely attached on an emotional and on a personal level. (P6 – Intellectual Disability Service)

**Supporting and empowering**

The reciprocal and shared learning relationship between specialist palliative care and intellectual disability services was related to dispelling fear and providing mutual support in working with people with intellectual disabilities who were dying.

Increasing confidence in working with intellectual disability. This was linked to the feelings of fear, which specialist palliative care services had in this area of
practice, and which could be addressed through joint working:

I think I would be happier now that we have good established links and I think it was the recognition of my own inabilities and the limitations of my practice in relation to this group. (P3 – Specialist Palliative Care Service)

For hospice staff, the Marie Curie and the McMillan staff, this is new and they are afraid and we need to ease that fear because … these people are the same as everybody else but just have difficulty in expressing their needs or their pain. (P14 – Intellectual Disability Service)

Increasing confidence in working with death and dying. This described the difficulties that intellectual disability services experienced in caring for someone who was dying and how they could be empowered by the support of palliative care services:

There was a number of staff found it very difficult … some of the staff had never seen anybody die, so it was that whole gentle, teaching on what happens as somebody is approaching death, when somebody actually dies. (P3 – Specialist Palliative Care Service)

I think with the involvement of the palliative care team it certainly gave us the confidence … to work with this lady, I think there would have been issues had we not had the team. (P6 – Intellectual Disability Service)

**Partnership in practice**

This reflected the benefits, challenges and enablers to collaborative working:

**Benefits of partnership.** One important outcome was the person being able to die in their place of care, with continuity of care by familiar people:

They could see in action palliative care at it’s best and it had a good outcome for the organisation because the staff worked to their finest level – the patient got to die in their place of care, the family were content. (P3 – Specialist Palliative Care Service)

Another outcome was the fusion of knowledge and skills between both services which appeared to enable a more robust assessment:

The involvement of the palliative care team … that’s imperative – the expertise and the skills that we don’t have … symptom management and the whole assessment process. (P6 – Intellectual Disability Service)

It (pain assessment) was in partnership again, they (learning disability services) knew her. They knew that when they might moved her, her face was contorted. It maybe wouldn’t be crying as I would have cried or you, but they knew that she was crying, so that’s when we looked at the pain control. (P13 – Specialist Palliative Care Service)

**Enabling partnership.** This in working and learning identified strategies to promote partnership. These were as follows: knowing how to contact services, ‘regional meetings’, joint ‘study days’ and joint working or shadowing in both clinical areas. The role of the general practitioner (GP) in early identification of need and specialist referral was highlighted:

I think there needs to be a greater appreciation of patients with learning difficulties in primary care, then they would come to the attention of the palliative care specialists at an earlier stage and probably better care can be delivered. (P17 – Specialist Palliative Care Service)

Comments showed the importance of professionals seeing the need for joint working and acknowledging their knowledge deficits:

They recognised that they had limited knowledge and understanding in palliative care, and the same for myself in learning disabilities. We were open with each other and we planned that care together … it was a two way process. I relied on them and vice versa. (P29 – Specialist Palliative Care Service)

**Challenges and barriers to partnership.** These revolved around the ‘medical’ versus ‘social’ model of care, time, lack of access and limited referrals to specialist palliative care services. Other challenges were around mistrust between people, at a human level, coming together to collaborate:

I think its difficult because we are slightly ‘siloed’ and slightly ostracised from the health service in palliative care services or in learning disability and that bruises us a little bit and makes us nervous to becoming too involved. (P1 – Specialist Palliative Care Service)

If personalities were involved … where maybe learning disability nurses feel that they are losing ownership … or that they are being told what to do. (P6 – Intellectual Disability Service)

**Discussion**

Based on the findings from the two phases of the study, a partnership framework for specialist palliative care and intellectual disability services was developed (Figure 1). This presents the context in which palliative care is delivered and illustrates other partnerships and services which may be present such as generalist palliative care, primary care, cardiac or respiratory services.

This framework adapts the conceptual model proposed by Boydell et al.\(^\text{19}\) in relation to this group of people and
similarly also focuses on connections, learning, actions and impacts relating to partnership practice. The data from the study have contextualised this in relation to partnership between specialist palliative care and intellectual disability services. The large arrows point to the core of the model showing the provision of optimal palliative care to be delivered to people with intellectual disabilities and family carers through partnership. Previous studies indicated that joint working and learning also takes place between people with intellectual disabilities and services and between family carers and services. However, optimal care will be made possible by collaborative working between generalist palliative care services and services for people with intellectual disability supported by other specialist services and primary care. Key challenges around the partnership are identified, but information obtained in this study suggests ways of overcoming them.

A strength of this study is that intellectual disability and specialist palliative care services contributed to the data collected and informed the emerging framework for partnership practice. This includes half of the learning disability services in the region.

**Connecting and enabling partnership**

Partnership between specialist palliative care and intellectual disability would be enabled by a willingness to learn from each other and recognition of one’s own knowledge deficits. Professionals who had experienced this collaboration reflected on case scenarios about how this partnership had empowered them in providing end-of-life care to someone with an intellectual disability. This finding is supported by other studies. However, a previous study has shown that willingness for these two services to collaborate was not enough to make it happen. It is recognised that interdisciplinary education is an antecedent to collaborative working and the limited uptake of professional education in this area of practice needs to be addressed.

At a human level, it was also clear from the findings that working together required a relationship of mutual trust and respect. Narratives from the interviews, and case scenarios, provided evidence that relationships, centred on trust and respect for each other’s knowledge base and skills, could dispel fear and mistrust which may have been present possibly due to services working in isolation and lack of familiarity with their different roles and philosophies.

**Partnership in action**

A level of partnership exists between specialist palliative care and intellectual disability services which can be nurtured and built upon. However, joint working appeared to be nurse to nurse and this needs to become more interdisciplinary across settings.

For partnerships to occur, systems and processes had to be in place for intellectual disability and specialist palliative care and learning about the connection of the two is needed. This framework provides a building block for future research and practice in this area.
palliative care services to come together. Joint learning to promote a greater understanding of service roles and philosophy was thought necessary and should commence in undergraduate education across health and social care. This mirrors current policy recommendations for palliative care principles and philosophy and learning disability awareness to be a core part of undergraduate curricula. Global competencies in palliative care have also highlighted the need for care to be tailored for people with intellectual disabilities and for professional self-care in dealing with death.

Impacts/benefits of partnership

Important outcomes of collaboration were apparent when it did occur. Persons with an intellectual disability had continuity of care and were enabled to die in their place of care, and if dying in other settings could still be cared for by people familiar to them and with them.

Through joint working, professionals had been able to more robustly assess and meet the holistic needs of people with intellectual disability at the end of their life. This appeared to happen through fusion of knowledge and skills in the two services and through having shared goals with the person with intellectual disability and those who matter to them.

Challenges to partnership

Constraints or barriers to partnership were also identified. One of these was a historical issue around the hurt or bruising, which appeared to be felt by staff in both services, when their contribution was not appreciated. Yet the examples of good practice shown in this study are evidence that services can engage with each other and build up trust leading to an effective collaborative working arrangement. It was also clear that the rationale for collaboration had to be supported at all levels, including managerial.

Specialist palliative care services reported limited and late referrals of people with intellectual disabilities, as has been noted in other studies internationally, which was a constraint to collaboration, in that it limited the capacity to develop partnerships. This issue will require to be addressed if palliative care is to be accessible to all.

Despite the challenges around the diversity in service development and delivery in different countries, the learning from this study could help to address the international issue of access to quality palliative care for people with intellectual disabilities and the related professional deficits in knowledge and skills.

Conclusion

This study has provided new insights into partnership working between specialist palliative care and intellectual disability services. A best practice framework is proposed which can be used to guide service developments such as improved education and training of service staff. The framework should be further explored with services for other groups of people in end-of-life care such as those for people with mental health needs or chronic disease.

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Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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References


15. Persaud S. *Staff perceptions about the nature and extent to which palliative care and learning disability services work jointly in the provision of high quality services for people with learning disabilities who are terminally ill*. Unpublished work for New Researchers Training Programme, The Trent Institute for Health Service Research, 2001.


