A convergent parallel mixed methods study of the end-of-life care experiences of people with intellectual disability in Ireland: Lessons learned from IDS TILDA.

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List of Abbreviations

Community Palliative Care: CPC

End-of-life care: EOLC

Healthcare professional: HCP

Health and social care professional HSCP

Intellectual disability: ID

Palliative care: PC

Specialist palliative care: SPC

Specialist palliative care in-patient unit (hospice): SPC IPU

The Irish Longitudinal Study of Ageing: TILDA

The Intellectual Disability Supplement to the Irish Longitudinal Study of Ageing: IDS-TILDA

Abstract/ Summary

Palliative care is a vital intervention to relieve the suffering of people living with, and dying from, life-limiting conditions. However, people with an intellectual disability experience inequity in their access to, and experience of, palliative care. [2] Progress in addressing care deficits has been slowed by the fact that the evidence-base is largely limited to small scale, descriptive studies. [3] The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) is a longitudinal study studying the circumstances of adults with an intellectual disability aged ≥40 years who are resident in Ireland. [4-8] It offers opportunity to study palliative care experience in a rigorous manner.

The IDS-TILDA End-of-Life Care study is a convergent parallel mixed methods study situated within IDS-TILDA whose purpose is to understand the end-of-life care experiences and service utilisation of people with an intellectual disability in Ireland from the perspective of bereaved caregivers. Data is collected using survey and interview methods.

Findings demonstrate that decedents were reported by carers as experiencing need in physical, emotional, psychosocial, spiritual, communication, decision-making, continuity of care and disability-related domains. They emphasised the importance of including family, intellectual disability staff and peers within the 'unit' of palliative care provision. A conceptual model of the Intellectual Disability Palliative Care Ecosystem was developed and tested and provided comprehensive insight into factors influencing need and complexity. Strengths in palliative care provision were observed; 43.6% of the population accessed specialist palliative care, quality of care was rated highly and 50.7% died in their usual place of care. Areas of deficit warranting attention were observed; they included addressing communication, spirituality, support for peers and staff.

The study provides a comprehensive understanding of the range of factors influencing whether people with an intellectual disability 'live well' with a life-limiting condition and experience a 'good death'. Future waves of IDS-TILDA offer opportunity to understand which combinations of services and support are most strongly associated with cost-effectiveness and benefit.

Lay Abstract

Palliative care is a type of care given to people who have serious illness. It improves the quality of life of the person who is unwell and helps families cope. It does this by easing pain and other symptoms, providing emotional and counselling supports and by giving practical help. Palliative care should be given to any person who is suffering because of serious illness but we know that sadly this does not always happen. [9] Research has shown us that people with an intellectual disability are a group of people who get palliative care less often than the general population. [2] It has also told us that when people with an intellectual disability get palliative care, it isn't always provided in a way that meets their needs. [3] We need to understand why people with an intellectual disability aren't getting the kind of palliative care that they need.

IDS-TILDA is a large research study that has been running in Ireland since 2010. [4-8] It has enrolled 753 people with an intellectual disability into the study and it meets with them every three years to find out how they are feeling and what is happening to them in their lives. Sadly, some people with an intellectual disability who were involved in the study have died. We want to find out how well they were cared for and understand what helped (or didn't help) them before they died. We carried out a study called the IDS-TILDA End-of-Life Care study that has collected this information. It did this by asking the carers of the people who died questions about their care in a written questionnaire and in an interview.

We found that people with intellectual disability experience the same needs as the general population before they die, but they also experience special needs that healthcare services must respond to. These needs include ensuring that people with intellectual disability are cared for by familiar, trusted people; that individual styles of communication are understood and supported; that signs of distress are recognized and that reasonable adjustments are made for disability. Healthcare services need to adapt their services and provide care that is personalised to people with an intellectual disability. Services also need to extend the care they provide to provide support to the families, friends, and staff of people with an intellectual disability because these groups of people can all find it hard to cope too. Although we found areas where care still needs improvement, we did find positive examples of care also. We found that intellectual disability organisations and hospices often work together to provide care. When this happens, we found that the person with serious illness often gets good quality care.

Outputs

Ryan K. The Process of Dying. Stancliffe RJ, Wiese M, McCallion P, McCarron M, editors. End of life and people with intellectual and developmental disability: Contemporary issues, challenges, and practice. Palgrave McMillan; 2022.

Ryan K, McCallion P, McCarron M. P 7.019 Specialist Palliative Care Provision to People with Intellectual Disability - Progress Yet Challenges Persist. Poster Presentation, European Association for Palliative Care, Rotterdam 15-17 June 2023.

Chapter 1. Introduction

1.1 Introduction

This chapter provides introduction, contextualisation, and overview of the structure of this dissertation. It begins by providing a statement of the problem that this research- the IDS-TILDA End-of-Life Care study- seeks to address. Next, it introduces IDS-TILDA (also known as the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing) which is the longitudinal study within which the End-of-Life Care Study is nested. The focus then moves from IDS-TILDA to specific consideration of the End-of-Life Care Study- the aims and objectives of the End-of-Life Care Study are described, and its potential contribution to policy and practice considered. The final section of this chapter provides an overview of the structure of the remainder of the dissertation.

1.2 Statement of the problem

1.2.1 Palliative Care as a core component of healthcare

Palliative care is a vital intervention to relieve the suffering of people living with, and dying from, life-limiting conditions. It is fundamental to health and human dignity, and many consider it to be a basic human right. [10] The United Nations Committee on Economic, Social and Cultural Rights asserted that 'States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons . . . to preventive, curative and palliative health services.' [11] The Report of the 67th World Health Assembly additionally addresses the strengthening of palliative care as a component of comprehensive care throughout the life course. [12]

Palliative care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness- whatever the diagnosis. [13, 14] The goal is to improve quality of life for both the patient and the family. Palliative care is appropriate at any age and at any stage in a serious illness and can be provided together with curative treatment. This integrated model of palliative care provision is broader than the original idea of 'terminal' or 'end-of-life' care but does still include end-of-life care. As Cicely Saunders, the founder of the modern hospice movement, stated 'You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.' [15]

1.2.2 Palliative care provision in Ireland- demographic challenges and service configuration

As a result of Ireland's ageing population, the number of people dying annually from a condition associated with palliative care need aged 50+ years is estimated to rise to 40,355 by 2046. [16] This represents a rise of 84% from 2016 baseline figures of 22,806. Moreover, the number of people who are not in their last year of life but who are living with a chronic condition associated with palliative care need is estimated to rise to 548,105 people (an increase of 89%). While these demographic changes are indicative of the successful increases in longevity, they also point to the increased demands that will be placed on systems that provide care. Ireland is already experiencing challenges in health and social care provision, and it is universally accepted that reform of our health services is required to meet these growing needs.

The solution proposed by the Oireachtas Committee on the Future of Healthcare is the establishment of a universal, single-tier health service where patients are treated based on need and where health services are re-oriented towards the provision of integrated primary and community care. Cross-party political consensus resulted in the publication of the 'Houses of the Oireachtas Committee on the Future of Healthcare "Sláintecare" Report' in May 2017. [17] The report represents a high-level policy roadmap to the reform of Irish healthcare, and it has guided re-organisation and development of services in recent years. Of particular importance to palliative care is Sláintecare's recommendation that universal palliative care services are provided within five years of report implementation.

Following publication of the Sláintecare Implementation Strategy and Action Plan 2021-2023, the Minister for Health convened a Steering Group in 2022 to develop a new policy for adult palliative care services. [18] In line with Sláintecare's vision, the Steering Group have been tasked with consideration of how best to improve access and address gaps in generalist and specialist palliative care to ensure patients and their families receive the right care at the right time in the right place. When published, the document will replace the Report of the National Advisory Committee on Palliative Care (NACPC Report) which has been national policy since 2001. [19] Implementation of the NACPC Report has been associated with general development of palliative care services and has led to Ireland being ranked fourth in the 2015 Economist Intelligence Unit "Quality of Death Index". [20] Service provision is organized according to the principles of the NACPC Report and the National Clinical Programme Model of Care for Adult Palliative Care Services. [21] Accordingly, services are organized into 'specialist' and 'generalist' services and a needs-based approach to service provision is adopted.

Generalist palliative care services are those services whose staff have ‘palliative care approach’ or ‘generalist palliative care’ competences [22] and who can meet the needs of patients with relatively uncomplicated palliative care problems. Generalist services typically do not focus solely on palliative care provision, rather they provide palliative care alongside other services e.g., General Practice, hospital-based services, residential care. Specialist palliative care services, in contrast, are staffed by healthcare professionals with specialist palliative care competences and they focus on the provision of palliative care only. In the needs-based model, patients are stratified to receive services based on complexity of need. Quality palliative care provision is best realised when strong networks exist between generalist and specialist palliative care providers - working together to meet the needs of all people. [23]

1.2.3 Palliative care provision for people with an intellectual disability in Ireland

Importantly, the NACPC Report acknowledged that not all populations experience equitable access to palliative care and noted that people with an intellectual disability might have ‘particular needs’ that required specific consideration. [19] Internationally, there is evidence that people with an intellectual disability lack equitable access to healthcare generally, [24, 25] and palliative care, specifically. [26-28] Reasons for inequitable access to palliative care services are thought to relate to issues such as late diagnosis, lack of recognition of need, lack of recognition of dying and poor integration between specialist palliative care and intellectual disability services. [29-33] Even when a person with intellectual disability is in receipt of palliative care, further barriers to effective care have been observed. [33-35] A recent systematic review by Adams et al. described issues relating to staff education, communication, collaboration, and health and social care delivery negatively impacting on care. [2] While descriptive studies in Ireland have suggested that people with an intellectual disability experience inequitable access to and experience of palliative care, the the extent to which national palliative care policy and practice meet the needs of people with an intellectual disability is not known with any certainty. [36-38] Moreover, the national Adult Palliative Care Services Model of Care does not yet contain specific guidance on what ‘particular needs’ the population of people with intellectual disability might have or how services should be tailored to meet those needs. [21]

The increase in life expectancy that has occurred in recent decades in the population of people with an intellectual disability has been striking. In Ireland, there was an average 10-year gain in life expectancy over the 10-year period to 2012 [39] although this has since plateaued. [40] Increased life expectancy means rising prevalence of old age, frailty, dementia, multimorbidity and their associated needs. [8, 16, 41] Services that were developed with the purpose of enabling people with an intellectual disability to live ‘ordinary lives in ordinary places’ [42] are now facing issues associated with helping people to ‘live until they die’. Moreover, the country continues to grapple with the historic legacy of having provided institutionally based care with little formal oversight or regulation. Although a 2011 report [43] committed to closing all congregated settings by 2018, approximately 2,000 people were still living in institutions in 2019. [44] The ageing of the population of people with an intellectual disability further challenges the commitment to providing community-based care, particularly towards the end-of-life. The case for developing a robust evidence base to inform practice and the forthcoming new palliative care policy is clear.

1.3 Intellectual Disability Supplement to the Irish Longitudinal Study of Ageing

1.3.1 Background and purpose

The Intellectual Disability Supplement to the Irish Longitudinal Study of Ageing (IDS-TILDA) is a large, prospective, cohort study of the social, economic and health circumstances of people with an intellectual disability (ID) aged 40 and over in Ireland. [4-6, 8] It is a sister study of the Irish Longitudinal Study of Ageing (TILDA) which was established to address the challenges and opportunities associated with population ageing and to provide an evidence-base with which to inform policy and practice. [45, 46] IDS-TILDA was similarly conceptualised to make an original and substantive contribution to the lives of people with an intellectual disability. In fact, is the only study able to directly compare the ageing of people with an intellectual disability with the general ageing population due to its unique methodology.

High-quality population-based studies have an invaluable role to play in health sciences research in exploring and understanding the many influences that shape people’s lives. They are powerful tools providing insights at both individual and group levels and establishing a sequence of events over time. Longitudinal research methods are a mainstay of gerontological research, providing myriad understandings into the process and experience of ageing and helping differentiate between correlation and causation. The insights generated from longitudinal studies have contributed to advances in health and social care and studies share the overall goal of improving the health and wellbeing of older people. While longitudinal studies of ageing that involve the general population are well established, the Intellectual Disability Supplement to the Irish Longitudinal Study of Ageing (IDS-TILDA) is the first of its kind in Europe.

The objectives of IDS-TILDA are to:

- Understand the health characteristics of people ageing with an intellectual disability,
- Examine the service needs and health service utilization of people ageing with an intellectual disability,
- Identify disparities in the health status of adults with an intellectual disability as compared to TILDA's findings for the general population.
- Support evidence-informed policies, practices, and evaluation.

1.3.2 Recruitment

The original wave of IDS-TILDA was sourced through the National Intellectual Disability Database (NIDD). [47] The NIDD is a service planning tool designed to capture data on the usage of and the need for specialist disability services among people with intellectual disability. It comprises approximately 28,000 records created annually, and it is administered by the Health Research Board. The NIDD outlines the specialised health services currently used or needed by PWID, and its data content includes personal details of recipients including date of birth, gender, area of residence and level of intellectual disability. In 2017, the NIDD was merged and re-developed with the National Physical and Sensory Disability Database (NPSDD) to form one system – the National Ability Supports System (NASS).

Inclusion criteria for the IDS-TILDA sample are:

1. Age ≥40 years,
2. Registered with NASS/ NIDD,
3. Written informed consent to participate and/or family/guardian written agreement (where required).

The age-related inclusion criteria for IDS-TILDA were lower than TILDA (≥55 years) because PWID age prematurely and have a lower life expectancy compared to the general population.

The first wave of IDS-TILDA was drawn randomly from the 2008 National Intellectual Disability Database. It was anticipated that a participation rate of 45-50% would be achieved, and therefore a random sample of 1800 registrants who met IDS-TILDA inclusion criteria was generated and those individuals were invited to participate in IDS-TILDA. The final Wave 1 sample comprised 753 individuals, representing an overall response rate of 46%. The sample was equivalent to 8.9% of the total population aged 40 and over registered on the NIDD database in 2008.

IDS-TILDA data collection began in 2010, and subsequent data collection has been conducted in waves. Follow-up occurring at Wave 2 confirmed that a number of the original 753 IDS-TILDA participants had died. [6] Recognising the importance of understanding the end-of-life care experience of people with intellectual disability, the IDS-TILDA End-of-life Care Study was conceptualised.

IDS-TILDA's sister study, TILDA, also conducts end-of-life interviews with family members or close friends if follow-up confirms that a TILDA participant has died. The interview comprises eight topics focused on demographics, disability, and level of assistance in the last three months of life, physical health in the last year of life, behavioural health, cognitive function, and mood.

1.4 Aim and objectives of the IDS-TILDA End-of-Life Care Study

The IDS-TILDA End-of-Life Care study is a convergent parallel mixed methods study whose purpose is to understand the end-of-life care experiences and service utilisation of people with an intellectual disability in Ireland from the perspective of bereaved caregivers.

The study's objectives are to address key gaps in the knowledge base regarding palliative care provided to people with an intellectual disability in Ireland by investigating:

1) The trajectory of illness and cause of death of IDS-TILDA decedents.
2) Place of care and place of death.
3) Services utilised in the last three months of life.
4) Respondent experience of palliative care provision.

1.5 Value of the IDS-TILDA End-of-Life Care study

Little is known of the quality of palliative care provided to people with an intellectual disability in Ireland, even though Ireland has well-developed palliative care services. [20, 48] In common with the international literature, people with an intellectual disability experience in Ireland experience higher mortality rates and shorter life expectancy than the general population. [39] Exploratory studies have also suggested that people with an intellectual disability are at risk of poorer end-of-life care experiences. [36, 37, 49] Despite awareness of these inequalities, issues of methodology have limited advancement of knowledge on end-of-life care for people with an intellectual disability and service development. [50] While a growing number of studies have provided experiential data that have described issues and identified problems, the lack of reliable and representative information has acted as a barrier to developing effective strategies and solutions. [51]

IDS-TILDA affords a unique opportunity to explore the topic of end-of-life care provision for people with an intellectual disability in a methodologically rigorous manner through the voice of bereaved carers. Given that IDS-TILDA is primarily focused on understanding the experience of ageing, the IDS-TILDA End-of-Life Care study is nested within IDS-TILDA and was conceptualised to specifically focus on the last period of life. In keeping with the ethos and values of IDS-TILDA, the study was designed to make an original and substantive contribution to the lives of people with an intellectual disability. Generating understanding of trajectory of illness, service utilisation and the experience of receiving and providing palliative care will help provide greater knowledge of the range of factors influencing whether people with an intellectual disability 'live well' with a life-limiting condition and experience a 'good death'. Findings will be presented in practical and actionable ways to increase likelihood of impact on policy and practice, and they will make an original and substantive contribution to the evidence base.

1.6 Thesis outline

Having provided background and context to this study in the opening chapter of this thesis, Chapter 2 will present an integrative literature review that was conducted with the dual purpose of synthesising evidence regarding the palliative care needs of people with intellectual disability and those close to them, and synthesising key elements associated with conceptualisation of complexity in palliative care provision for this population.

Chapter 3 presents a narrative of the methodology employed in the IDS-TILDA End-of-Life Study. This includes presentation of the historical foundations and philosophical underpinnings of mixed-methodology research, as well as the rationale for using a convergent parallel design. Sampling strategy, data collection procedures, instrumentation and method of analyses are described. The chapter concludes with ethical considerations relating to the study.

Chapter 4 describes the data obtained and the findings of analysis. Chapter 5 discusses findings in the wider context of the field. It considers how findings from the IDS-TILDA End-of-Life Study have advanced knowledge and what their implications are. Chapter 6 concludes with a concise summary that collates the findings of other chapters. Key findings and recommendations for policy and practice are presented.

Chapter 2. Literature review

2.1 Introduction:

The generalist–specialist model of palliative care has been adopted in the policies of many resource-rich countries (including Ireland) as a means of providing a universal approach for all people with a life-limiting illness regardless of care setting or diagnosis. [52] In this model, patients move between generalist and specialist palliative care services depending on the complexity of their need. However, challenges to implementation have been noted, including heterogeneity of component interventions, limited volume of evidence, [53] and a lack of common definition as to what constitutes complexity. [54, 55] With specific reference to palliative care for people with an intellectual disability, it is notable that Brereton et al. failed to find any reviews examining the provision of care to people with an intellectual disability in their systematic review of reviews of models of palliative care. [53]

As previously noted, theoretical and empirical work in recent decades has demonstrated that people with an intellectual disability suffer inequitable access to, and experience of health and social care generally, and palliative care specifically. Despite the growing body of literature focused on the topic, a picture of suboptimal care and outcomes persists. Moreover, the specific palliative care needs of people with an intellectual disability remain poorly understood, and there has been a lack of research into strategies to improve practice. [2] A move towards action in this area is long overdue. It is therefore proposed that establishing a common understanding and language for discussion would be a useful way of advancing the state of science towards interventional studies. The purpose of this integrative review is to analyse the concept of palliative care need and complexity relating to people with an intellectual disability and those close to them, and to develop a conceptual framework to guide future work.

Specifically, the review aims to:

- Synthesise the current evidence regarding the palliative care needs of people with intellectual disability and those close to them, and
- Synthesise key elements associated with definition of complexity in the provision of palliative care to people with an intellectual disability and those close to them.

2.1.1 Integrative literature review

An integrative review concept method was used to guide the analysis. This review method uses broad sampling to include past empirical or theoretical literature and uses evidence synthesis to provide a more comprehensive understanding of a particular phenomenon or healthcare problem. [56] Integrative reviews are the broadest type of research review methods and have specific value when dealing with complex or ambiguous topics and when aiming to develop a holistic understanding of topics, present the state of the science and contribute to theory development. [57] As such, this approach was felt to best match the aim and perspective of the research project.

2.1.2 Theoretical models of complexity in palliative care

Complexity is broadly defined as the nature of patients' situations and the extent of resulting needs and care demands. [58] Interest in the concept of complexity in palliative care has been described as arising from a need to answer a number of questions: understanding factors that influence patient experience; identifying factors that determine resource utilisation and cost; and describing factors impact on the need for generalist, specialist or integrated service provision. However, to date, complexity in palliative care remains an ill-defined concept that lacks a standard manner of assessment or measurement. [59] In response to this gap in understanding, Hodiamont et al., [60] and Pask et al., [61] have produced papers in recent years that have engaged in consideration of the conceptual basis of complexity and definition of the factors determining complexity.

Hodiamont et al. [60] used empirical evidence derived from professional expert interviews. They developed a conceptual model by locating the complex problem 'palliative care situation' in a complex adaptive systems framework. In this model, three systems were identified to describe the overall complex adaptive system: The system patient, the social system, and the system team. System elements from all three systems are proposed to interrelate with each other as well as with the environment and to modulate the overall system behaviour. The model draws attention to the fact that component parts or elements cannot be understood independently or separated from the overall system.

Pask et al. developed a conceptual framework of complexity based on empirical evidence derived from patients, family carers and professionals. [61] It adapts Bronfenbrenner's Ecological Systems Theory, [62] placing the patient at the centre of the framework and explaining how complexity goes beyond the individual and is shaped by interactions with context and environment. In Pask's model, complexity is characterised in terms of microsystem, mesosystem, exosystem, macrosystem and chronosystem levels, and relationships between components are dynamic and cumulative in their impact. Bronfenbrenner's theory of human development is a theory that was, until Bronfenbrenner died in 2005, in a continual development. [62-69] While this is true of many theories, it is something that can lead to conceptual incoherence when researchers use earlier versions or a limited set of concepts from the theory without explicitly stating that they are doing this. [70] The mature form of Bronfenbrenner's theory is the Process–Person–Context–Time model (PPCT) model. [69] Pask et al. explain that they primarily draw from Bronfenbrenner's theory of person-context interaction and it is clear that not all of the elements of Bronnfenbrenner's model are utilised in their work. Table 1 provides an overview of the five systems of Bronfenbrenner's theory utilised by Pask et al.

Table 1 The five systems

Contextual component	Description
Microsystem	The smallest and most immediate environment in which the patient lives. Each microsystem is made up of people, their activities, their relationships with each other, and the roles that they play. The 'ontosystem' is a term that refers to elements of the microsystem that relate to the patient's personal biological dispositions and psychological characteristics.
Mesosystem	The interrelations between microsystems.
Exosystem	The settings that the patient does not participate in, but which affect or are affected by what happens in the patient's mesosystem.
Macrosystem	The regularities or patterns within micro, meso and exosystems characteristic of a particular group of people or region
Chronosystem	The passage of time

Theoretical framework utilised

Pask's adapted model of Bronfenbrenner's Ecological Systems Theory was chosen as a theoretical framework to guide data analysis for the integrative literature review. The framework was selected for several reasons. First, Bronfenbrenner's model is a theory of development, and this emphasis was felt to be aligned with the philosophical underpinning of palliative care that the final stage of life is one that can be characterised by growth or despair. Second, Bronfenbrenner's model merges developmental and ecological views, and points to the interrelatedness of the person and living system in which she or he is participating. The model demonstrates that to be human is to be relational and that wellbeing is always realised in a community. Third, the ecological perspective is one that offers a comprehensive, systems-based understanding of development and well-being. Such a perspective offers a useful framework for the development of interventional strategies.

It is important to note that use of Pask's model directs the attention of this review to the identification of the component elements of ecological systems that shape the development of palliative care needs and that influence their complexity. Consideration of other aspects of Bronfenbrenner's model lies outside the review's scope.

2.2 Methods

As with a systematic review, an integrative review requires a transparent and rigorous systematic approach. [71] This review was conducted following the methodology outlined by Whittemore and Knafl. [72] Work was organised according to the following five stages: (1) problem identification, (2) literature search, (3) data evaluation, (4) data analysis, and (5) presentation of findings, see Table 2. Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines framed reporting of the review. [73]

Table 2 Five stages of integrative review

Stage of review	**Illustration of decisions and issues**
Problem identification	The specific palliative care needs of people with an intellectual disability remain poorly understood, and there has been a lack of research into strategies to improve practice. Greater understanding of the concept of palliative care need for people with an intellectual disability is proposed as a useful way of establishing a common language for discussion and advancing the state of the science towards interventional studies. The purpose of this integrative review is to analyse the concept of palliative care need and complexity as relating to people with an intellectual disability and those close to them.
Literature search	Having a specific focus on description of palliative care need experienced by people with intellectual disability and those closest to them facilitated the literature search stage. A systematic search was carried out in the following databases: PubMed, Embase, Cinahl Plus, Google Scholar, PsychINFO, Web of Science and Cochrane Central Register of Controlled Trials between 1 January 2000- 1 June 2022. Following screening and review, relevant sources were reduced to 50 reports.
Data evaluation	Data were extracted from original reports using an extraction template structured to summarise study aim, sample characteristics and methods, in addition to evidence relating to palliative care need and complexity. Criteria from the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI) were used to guide quality assessment.
Data analysis	A hybrid approach of qualitative methods of thematic analysis was utilised in data analysis.
Presentation	A synthesis in the form of a model was developed to comprehensively portray palliative care need and complexity experienced by people with an intellectual disability and those closest to them (family, peers, formal caregivers).

2.3 Literature search

A systematic search was carried out in the following databases: PubMed, Embase, Cinahl Plus, Google Scholar, PsychINFO, Web of Science and Cochrane Central Register of Controlled Trials between 1 January 2000- 1 June 2022. Table 3 details inclusion and exclusion criteria:

Table 3 Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
2. Report with or about adults with an intellectual disability and life-limiting conditions and/or those closest to them (family, formal and/ or informal caregivers).	1. Questionnaire validation studies, literature reviews, conference abstracts, pre-prints, commentaries
2. Data presented on the palliative care needs of adults with an intellectual disability and/ or those closest to them.	2. Grey literature
3. Peer-reviewed journal.	
4. Written in English.	

The search included MESH terms and keywords, and each keyword was combined with Boolean operators (and, or, not); truncation was used to expand the number of hits. An example of a search strategy is provided in Table 4. The reference lists of the included articles were hand searched. [74]

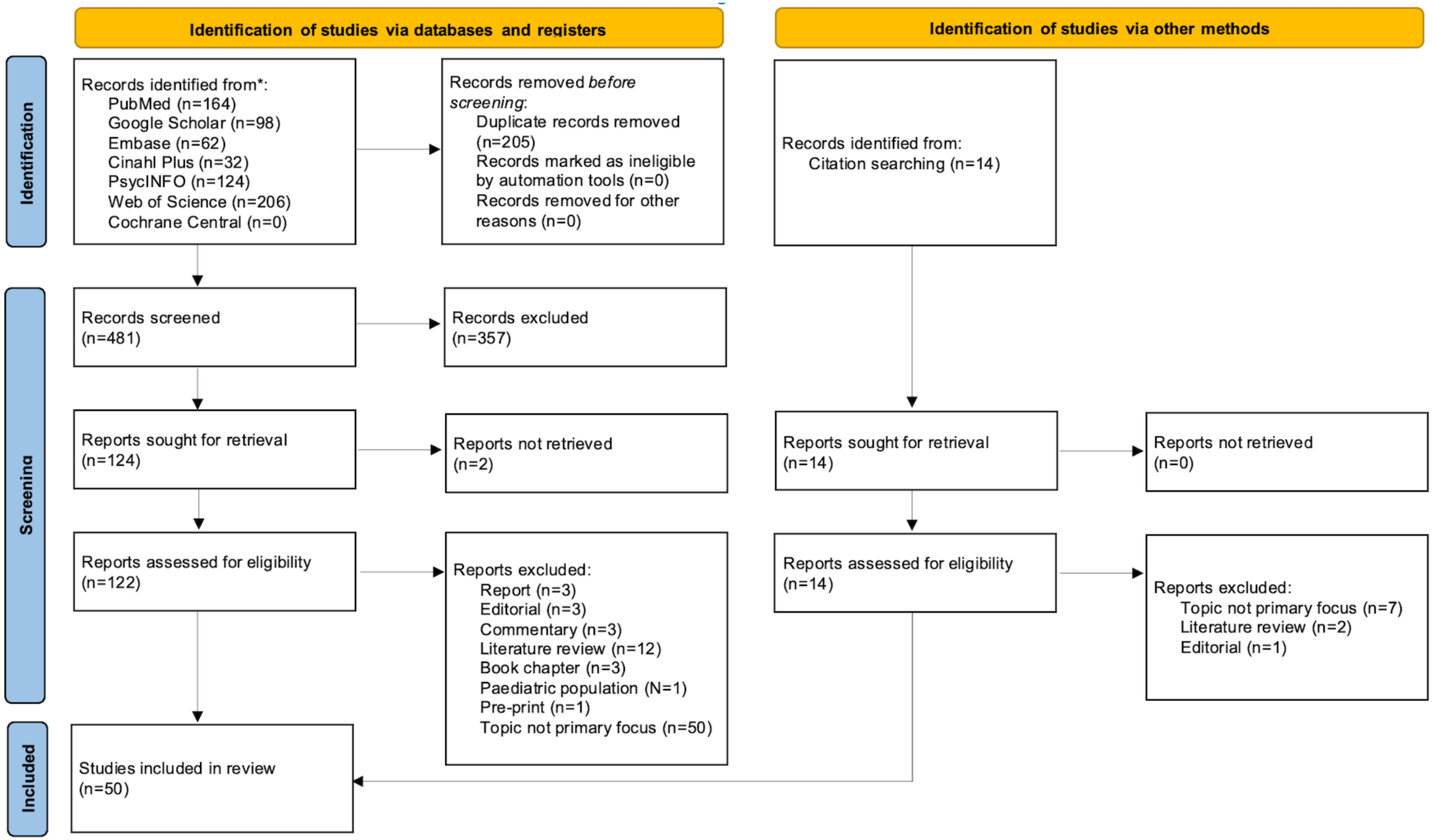
Table 4 Search strategy

Set no.	Searched for	Results
S1	(su("palliative care") OR su("end of life care") OR su("terminal care") OR su(Palliat*) OR su(hospice*) AND su("comfort care")) AND PEER(yes)	81940
S2	(su(intellectual disability) OR su(adult developmental disabilities) OR su(learning disability) OR su(mental* retard*) OR su("mental deficiency")) AND PEER(yes)	178942
S3	((su("palliative care") OR su("end of life care") OR su("terminal care") OR su(Palliat*) OR su(hospice*) AND su("comfort care")) AND PEER(yes)) AND ((su(intellectual disability) OR su(adult developmental disabilities) OR su(learning disability) OR su(mental* retard*) OR su("mental deficiency")) AND PEER(yes))	292
S4	((su("palliative care") OR su("end of life care") OR su("terminal care") OR su(Palliat*) OR su(hospice*) AND su("comfort care")) AND PEER(yes)) AND ((su(intellectual disability) OR su(adult developmental disabilities) OR su(learning disability) OR su(mental* retard*) OR su("mental deficiency")) AND PEER(yes)) AND stype.exact("Scholarly Journals")	288
S5	((su("palliative care") OR su("end of life care") OR su("terminal care") OR su(Palliat*) OR su(hospice*) AND su("comfort care")) AND PEER(yes)) AND ((su(intellectual disability) OR su(adult developmental disabilities) OR su(learning disability) OR su(mental* retard*) OR su("mental deficiency")) AND PEER(yes)) AND (at.exact("Article" OR "Report" OR "Case Study" OR "Undefined" OR "Evidence Based Healthcare") AND stype.exact("Scholarly Journals"))	263
S6	((su("palliative care") OR su("end of life care") OR su("terminal care") OR su(Palliat*) OR su(hospice*) AND su("comfort care")) AND PEER(yes)) AND ((su(intellectual disability) OR su(adult developmental disabilities) OR su(learning disability) OR su(mental* retard*) OR su("mental deficiency")) AND PEER(yes)) AND (at.exact("Article" OR "Report" OR "Case Study" OR "Undefined" OR "Evidence Based Healthcare") AND stype.exact("Scholarly Journals") AND la.exact("ENG"))	258
S7	((su("palliative care") OR su("end of life care") OR su("terminal care") OR su(Palliat*) OR su(hospice*) AND su("comfort care")) AND PEER(yes)) AND ((su(intellectual disability) OR su(adult developmental disabilities) OR su(learning disability) OR su(mental* retard*) OR su("mental deficiency")) AND PEER(yes)) AND (bdl(1007458) AND at.exact("Article" OR "Report" OR "Case Study" OR "Undefined" OR "Evidence Based Healthcare") AND stype.exact("Scholarly Journals") AND la.exact("ENG"))	124
S8	((su("palliative care") OR su("end of life care") OR su("terminal care") OR su(Palliat*) OR su(hospice*) AND su("comfort care")) AND PEER(yes)) AND ((su(intellectual disability) OR su(adult developmental disabilities) OR su(learning disability) OR su(mental* retard*) OR su("mental deficiency")) AND PEER(yes)) AND (bdl(1007458) AND at.exact("Article" OR "Report" OR "Case Study" OR "Undefined" OR "Evidence Based Healthcare") AND stype.exact("Scholarly Journals") AND la.exact("ENG") AND PEER(yes))	124

Initially, 686 records were identified. However, 205 were identified as duplicates, leaving 481 available for screening. Following screening of titles and abstracts, 124 records were sought for retrieval and a further 14 identified through hand-searching. Following retrieval and review of full text, 50 reports were excluded because they minimally addressed the concept of palliative care need, and 26 were excluded for other reasons. Ultimately, 50 articles met the inclusion criteria, see Figure 1.

Data were extracted from original reports using an extraction template structured to summarise study aim, sample characteristics and methods, in addition to evidence relating to palliative care need and complexity.

Figure 1 PRISMA flow diagram.[75]



2.4 Data evaluation

Given that a systematic research synthesis is attempting to answer a question using the findings of research evidence, it is important that the evidence is both trustworthy and relevant. A large number of published quality appraisal tools are concerned with the issue of trustworthiness of the studies in themselves with little reference to the review question, leading Whittemore and Knafl [72] to recommend that data are evaluated and scored according to key criteria relevant to the review rather than using method-specific approaches. A 'review-specific' approach has the advantage of incorporating consideration of relevance of topic focus, population focus or setting as well as rigour and appropriateness of methodology. In this integrative review, criteria from the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI) were used to guide quality assessment. [76]

In keeping with EPPI criteria, studies were assessed according to three parameters:

- Methodological quality and the trustworthiness of the results. [1]
- Methodological relevance defined as the appropriateness of the study design for answering the review question. [2]
- Topic relevance defined as the appropriateness of the topic in relation to the review question. [3]

A score out of three was given for each domain (1 = poor, 2 = acceptable, 3 = good) and a combined total score out of nine was generated. [4] No studies were excluded based on their quality score; for individual quality scores see Table 5.

Data display matrices were created incorporating the data extraction templates and the quality scores, see Tables 5 and 6.

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[1] Denoted as 'A' in Table 5

[2] Denoted as 'B' in Table 5

[3] Denoted as 'C' in Table 5

[4] Denoted as 'D' in Table 5

Table 5 Summary evidence table [5]

Author, year	Aim of study	Sample	Design	Analysis	Findings	Score
Bailey et al., 2016 [36]	To describe the provision of community nursing support for PWID and palliative/EOL care needs from the perspective of community nurse	94	Cross-sectional survey	Descriptive statistics	ID and PC are largely working independently of each other. Most nurses had limited experience of caring for PWID, & many felt that they lacked the knowledge & skills required. Emotional needs of PWID largely overlooked. Challenges included: understanding communication styles, late referrals, lack of time, knowledge & skills. Benefits of liaison between family & professional & nonprofessional carers noted. Findings point to the importance of teamwork, advance planning, knowing the person & best practice in providing PC for PWID through collaboration.	A=2 B=1 C=1 **D=4**
Bekkema et al., 2014 [77]	To describe how caregivers and relatives shape respect for autonomy in the EOL care for PWID and to discuss to what extent this corresponds with a relational concept of autonomy.	47	Case study	Inductive qualitative analysis using elements of thematic analysis	Respect for autonomy in the EOLC of PWID was mainly reflected in helping the person with an ID familiarise with 3 transitions: new information on the diagnosis & prognosis, changing care needs & wishes, & important decisions that were at stake. In respecting autonomy, relatives & caregivers encountered several challenges. These concerned ascertaining information needs, communicating about illness & death, inexperience in EOL care, eliciting current & hidden last wishes, the dependence of PWID & conflicting wishes. Several qualities were important for respecting autonomy: attention to information needs, connecting, recognising EOL care needs, giving space to show wishes and preferences & discussing dilemmas.	A=3 B=3 C=2 **D=8**
Bekkema et al., 2015 [78]	To address the following research questions: do relatives, ID care staff and ID physicians perceive a shift in their care approach and attitudes when the death of a person with an intellectual disability is imminent? And if so, what shifts in care approaches and attitudes do they perceive? And what values underlie these shifts?	47	Case study	Inductive qualitative analysis using elements of thematic analysis	5 shifts were found: 1) adapting to a new strategy of comforting care, taking over tasks & symptom relief, 2) interweaving of emotional & professional involvement, 3) stronger reliance on the joint interpretation of signals expressing distress & pain, 4) magnified feeling of responsibility in medical decisions, 5) intensified caring relationship between 'two families': relatives & care staff. 6 relational values were behind these shifts: 'being there' for PWID, 'being responsive' to the person's needs, 'reflection' on their own emotions & caring relationships, 'attentiveness' to wishes & expressions of distress, 'responsibility' for taking joint decisions in the best interests of the person, & 'openness to cooperation & sharing' the care with others.	A=3 B=3 C=2 **D=8**
Bekkema et al., 2016 [79]	To explore relevant dimensions of the care relationships in EOL care from the perspectives of people with mild ID in the Netherlands.	33	Focus groups	Nominal group technique	Two dimensions of care relationships were found: (1) 'Ascertain, record & honour wishes' of the ill person. Adequately dealing with care wishes, 'last wishes' & funeral wishes was of central importance: 'it's about their life'. We found an emphasis on control that seemed to reflect the participants' experience that respecting autonomy does not always happen. (2) 'Being there': Ill people need people who are there for him or her, practically, as well as emotionally, socially & spiritually. Participants placed specific emphasis on providing positive experiences.	A=3 B=3 C=2 **D=8**
Brown et al., 2003 [80]	To study how services could make possible an 'ordinary' death in the community for people with learning disabilities	21	Case study series	Not described	Documents how the service learned of the person's illness, how they mobilised services & made decisions, how agencies worked together and what support staff needed in the person's last months & weeks. Also considers the way staff, as individuals and as teams, made sense of their experiences & evaluated the input of other professionals.	A=2 B=1 C=2 **D=5**

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[5] PWID: people with an intellectual disability; ID: intellectual disability; PC: palliative care; SPC: specialist palliative care

Bycroft, 1994 [81]	To reflect on two closely linked incidents which occurred when the author was caring for the PWID & breast cancer & which influenced her practice as a Macmillan nurse	1	Case study	Not described	Case study provided with reflection on pain management, wound care, communication, relationship building with PWID and collaborative practice.	A=1 B=1 C=1 **D=3**
Cartlidge and Read, 2010 [82]	To identify what educational & preparation skills hospice staff felt were needed to enable them to feel confident in providing specialist PC to PWID.	26 + 17	Mixed methods- questionnaire and focus groups	Not described	Collaborative working of hospice staff alongside ID nurses was a great support. Importance of getting to know the person —building their trust & giving them more time. Discussing patients' health status, treatment compliance issues, understanding of conditions & gaining valid consent were difficult. Some staff did not appreciate what it meant to have an ID, & i what it meant to live with and ID and die with an ID. Staff found it difficult to manage a patient's specific behavioural problems. On occasion, PWID raised their voices when speaking with family members in the hospice corridors. Hospice staff recognized that sometimes PWID were not always treated as adults with equal rights & opportunities within the family context & their level of understanding of how they felt about this was often difficult to ascertain. This could make hospice staff feel uncomfortable & unsure on how to approach this.	A=1 B=2 C=1 **D=5**
Cithambaram et al., 2020 [83]	To illustrate the accounts of PWID & families regarding the need for information & decision-making at the EOL.	19	Semi-structured interview	Constant comparative (Grounded Theory)	PWID were comfortable with, & wished to know about, what was happening in their lives, including the existence of life-limiting conditions, so that they would be able to create a good plan for their future care. It was essential to create a plan of care that allowed HSCPs to provide excellent care & use of which prevented the occurrence of any ambiguity.	A=3 B=2 C=2 **D=7**
Cithambaram et al., 2021 [84]	To understand what constitutes good care at the end-of-life for PWID from the perspectives of both those with ID & their families.	19	Semi-structured interview	Constant comparative (Grounded Theory)	Providing personal care while vulnerable & dying, being with and communicating with the dying person, & meeting their spiritual needs, were considered as being essential at the EOL for PWID- thematic categories of "personal attention," "social connectedness," & "spiritual reconciliation."	A=3 B=3 C=2 **D=8**
Foo et al., 2021 [85]	To explore the experiences of SPC staff in talking with PWID about their dying and death, and factors that influence these conversations.	20	Semi-structured interview	Inductive analysis using thematic analysis	SPC staff did not consistently talk with PWID about their dying & death. Conversations were influenced by (a) the perceived capacity of PWID, (b) experience & expertise of PC staff, (c) the relationship between PC staff & dying person & (d) values of PC staff & other caregivers.	A=3 B=2 C=2 **D=7**
Forbat and Pekala Service, 2005 [86]	To use a theoretical & analytic model as a framework to shed new light on some of the core issues that influence policy and practice in supporting PWID & dementia in EOLC.	N/A	Theoretical paper	Utilisation of the hierarchy model within an approach called the Coordinated Management of Meaning, or CMM.	The hierarchy model is introduced as a tool to focus the attention of policy & practice on all aspects of caregiving. The article focuses on its utility in scrutinizing EOL & later stages of dementia by illustrating its use with 3 key areas in dementia care- nutrition, medical interventions, & the location of care provision. The model enables a focused approach to understanding how meaning is created within social interaction.	A=2 B=2 C=1 **D=5**
Gray and Kim, 2020 [87]	To assess DCWs' PC experience & training and their perceived training needs.	60	Focus groups	Descriptive statistics & thematic analysis	Participants reported limited experience in legal matters yet had substantial experience in assisting PWID with pain, distress & bereavement. Training was inadequate but desired for cultural competence, effective communication, post-death logistics & legal matters. Rural DCWs reported less PC experience & training than suburban counterparts.	A=2 B=2 C=2 **D=6**

Hussain et al., 2019 [88]	To understand the impact that EOL has on personal relationships for PWID.	35	Focus groups	Thematic analysis	Thematic analysis identified 3 key thematic areas: Relationships with Family, Relationships with Friends & Staff Roles. Relationships with Family had three sub-themes of 'Active & Ongoing', 'Active but Limited' and 'After Death'. Relationships with Friends had two sub-themes of 'Positive Experiences' & 'Negative Experiences', & Staff Roles had two sub-themes of 'Loss of Contact' & 'Default Decision Making'.	A=3 B=2 C=2 **D=7**
Kim and Gray, 2018 [89]	To explore direct care workers' experience with PC & challenges they faced.	54	Focus groups	Thematic analysis	Challenges workers faced and strategies they employed to meet PWIDD's needs were described using two main themes: ‘‘challenges'' and ‘‘meeting PWIDD's needs.'' The first theme encompassed difficulties in communicating with PWIDs, anxiety of anticipating death, & limited organizational resources or support. Empathy, extra attention, adaptation in care, & peer support comprised the second theme.	A=3 B=2 C=2 **D=7**
Kirkendall and Waldrop, 2013 [90]	To describe the perceptions of community residence staff who have cared for older PWID at the EOL.	8	Semi-structured interviews	Grounded theory techniques	4 themes illuminated unique elements of the provision of EOLC: (1) influence of relationships, (2) expression of individuality, (3) contribution of hospice, (4) grief & bereavement (5) EOLC challenges	A=1 B=2 C=2 **D=5**
Li and Ng, 2008 [91]	To identify expertise and deficits in the specific knowledge and practical skills of nurses in the care of dying patients with profound learning disabilities in one NHS Primary Care Trust in the UK.	5	Case study	Content analysis	Themes showed were 'certainty of knowing' about disease-related changes in patients' habits and behaviour & 'uncertainty and ambiguity' in the pathophysiology of advanced diseases & disease progression. This study interprets a lack of pathophysiological knowledge in both malignant & non-malignant diseases leading to delayed diagnosis and timely intervention. Timeliness of observation & intervention are emphasised.	A=1 B=1 C=2 **D=4**
Lindop and Read, 2000 [92]	To address the national PC issues in relation to PWID; to identify the current PC services provided by district nurses for PWID in North Staffordshire; to Identify, clarify & prioritize the professional & educational development needs of district nurses in North Staffordshire; to formulate a method of identifying the educational needs of district nurses in the role of PC providers for PWID	12 (focus groups); 109 (surveys)	Mixed methods- focus groups and questionnaire	Descriptive statistics & content analysis	The results demonstrated that the need to understand the nature of ID & associated effects is greater than understanding what patients are saying, interpreting nonverbal communication or understanding the level & structure of care provision & the accurate assessment of pain & other symptoms, or social competence. Understanding/interpreting non-verbal communication was a greater need than understanding the management of symptoms other than pain (P=0.05). However, the need to accurately assess & manage pain was greater than the need to understand/interpret non-verbal communication, assess healthcare needs & the level of social competence or manage symptoms other than pain (P=0.05). Gathering information from other appropriate carers was a greater need than understanding the level and structure of care provision or the accurate assessment & management of pain or other symptoms (P=0.00). However, assessing healthcare needs was of greater importance than gathering information from other appropriate carers.	A=1 B=1 C=1 **D=3**
McCarron et al., 2010 [93]	To understand the concerns of carers in ID services & PC services in supporting PWID & advanced dementia.	57	Focus groups	Thematic analysis	Two core themes: building upon services' history & personal caring—offering quality & sensitive care & supporting comfort and optimal death in persons with ID and advanced dementia. Challenges were raised for service systems in the areas of aging in place, person-centred care, & interservice collaboration	A=3 B=3 C=2 **D=8**
McCarron et al., 2011 [37]	To better describe the role and timing of PC in supporting persons with an intellectual disability & advanced dementia	57	Focus groups	Thematic analysis	SPC staff recognized that person-centred care delivered in ID services was consistent with palliative approaches, but staff in ID services did not consider advanced dementia care as ‘PC'. Both groups were unsure about the role of PC at early stage of dementia but appreciated SPC contributions in addressing pain & symptom management challenges.	A=3 B=3 C=2 **D=8**

McCarron et al, 2010 [94]	To understand staff perceptions of critical issues in caring for PWID & advanced dementia.	57	Focus groups	Qualitative content analysis	Staff identified three key themes: (1) readiness to respond to end-of-life needs, (2) the fear of swallowing difficulties, & (3) environmental concerns & ageing in place.	A=3 B=3 C=2 **D=8**
McKibben et al., 2020 [30]	To determine the informational needs of family caregivers of PWID who require PC.	38	Individual interviews and focus groups	Thematic analysis	Family caregivers reported information needs chiefly concerning the disease, financial entitlements, & practical support which could change over the disease trajectory. Findings evidence the expertise of long-term family caregivers, prior to the EOL. PC & ID teams acknowledged their role to work in partnership & facilitate access to information. Recommendations were mapped onto a co-designed logic model.	A=3 B=3 C=2 **D=8**
McLaughlin et al., 2015 [95]	To elicit the views of PWID, & their family carers concerning PC, to inform healthcare professional education & training.	22	Individual interviews and focus groups	Content analysis	PWID can have conversations about death & dying, & their preferred EOLC, but require information that they can understand. They also need to have people around familiar to them & with them.	A=3 B=3 C=2 **D=8**
McNamara et al., 2020 [96]	Use the perspectives of health professionals & paid carers to document the range of needs PWID experience during the last months of their lives	26	Semi-structured interview	Constant comparison	A range of challenges & unmet needs experienced by PWID are presented in themes: (1) accommodation setting at the EOL: dying 'at home'; (2) personal factors & networks: a circle of support; (3) EOL medical care and decision-making. Strategies to facilitate good EOLC & a model of care are presented.	A=3 B=2 C=2 **D=8**
Ng, 2003 [97]	To explore the educational base and needs of qualified care practitioners in ID settings in relation to death, dying & PWID.	25	Questionnaire	No	A lack of consistent policy in the recording of death in residential homes for PWID was highlighted; a lack of knowledge, particularly in psychosocial aspects and skills in care of dying persons. The importance of communication with PWIDs & their families was emphasised. It was recommended communication & interpersonal skills in the care & management of the terminally ill PWID be the core component in the nursing curriculum. Data support the notion that issues of LD override & obscure physical illness. Data highlights ambiguity in the use of concepts & terminology,	A=1 B=1 C=1 **D=3**
O'Sullivan and Harding, 2017 [98]	To provide a better understanding of the experience of support workers caring PWID nearing the EOL in residential settings.	13	Focus groups	Descriptive statistics &thematic analysis	6 themes: strong emotional bond and identification; collaboration with other services; training issues around the extended role; support within the organisation; relationship with family/ other residents; & grieving the 'losses'.	A=2 B=2 C=2 **D=6**
Rauf and Bashir, 2021 [99]	To describe some of the challenges in the delivery of palliative care in a complex situation and provide knowledge base to bridge those flaws.	1	Case study	Case study methodology	The various stages of a patient's journey from getting a life-limiting diagnosis to breaking bad news & dealing with the treatments and resulting complications need active involvement from the patient & their loved ones with healthcare professionals. It becomes more challenging if the patient has impaired mental capacity & cannot make his independent decisions as a result. The interplay of patient's wishes, the wishes of immediate relatives, the law of the land & clinician's role in becoming an advocate to safeguard patient's best interest has significant implications for all stakeholders & far-reaching consequences.	A=1 B=1 C=1 **D=3**
Read and Cartlidge, 2012 [100]	To explore the challenges to providing effective end-of-life care for PWID by using critical reflection from a nursing care perspective on an illustrative case study.	1	Case study	Case study methodology	Death occurs in a social context, & the social context Is crucial to providing appropriate EOLC. Needs of PWID discussed including importance of family relationship, supporting choice & autonomy, providing proactive supports & making reasonable adjustments to care. Value of education, training, reflective practice & collaborative working emphasised.	A=1 B=2 C=2 **D=5**

Ryan et al, 2010 [49]	To describe staff perception of the experiences of people with an intellectual disability when other service users die.	91	Focus groups	Framework analysis	Range of relationships observed between PWID living together but regardless of relationship, findings highlight the emotional impact of the death of a peer on PWID. Importance of same not always recognised by SPC staff. Impact exacerbated when sudden death occurs. Value of pro-active engagement and preparation highlighted but uncommonly occurs. Poor understanding can heighten distress. Family can have considerable influence as gatekeepers.	A=3 B=2 C=2 **D=7**
Ryan et al, 2011 [101]	To explore the attitudes, feelings & experiences of staff to the provision of PC to PWID	64	Focus groups	Framework analysis	Participants wanted to provide PC & felt the experience enriched practice. However, they were inadequately prepared to meet need & this often led to staff stress. Several issues appeared to heighten stress: situations when end-of-life care decision making was challenging, when staff felt ‘pushed out’ by relatives & when staff did not have sufficient support or time to provide care or mourn the loss of service users.	A=3 B=2 C=2 **D=7**
Ryan et al, 2011 [102]	To explore how staff manage communication about death and dying with PWID in a region in Ireland.	91	Focus groups	Framework analysis	Participants infrequently discussed death and dying with PWID. Participants operated most in suspicious awareness environments with people with mild-to-moderate ID, & closed awareness environments with people with severe ID. Most participants did not hold absolute opinions that talking about illness, death, & dying with PWID was "wrong." Rather, they were concerned that their lack of skill & experience in the area would cause harm if they engaged in open conversations. Relatives had an influential role on the process of communication. Participants were willing to consider alternative approaches if this would benefit PWID.	A=3 B=2 C=2 **D=7**
Ryan et al, 2016 [31]	To explore the nature and importance of the quality of relationship in the delivery of care.	91	Focus groups	Framework analysis	Staff valued their relationships with PWID who were using services & felt that the quality of their relationship affected its therapeutic potential. Participants described factors fundamental to the development of quality relationships. PC and ID staff commented on the importance of trust, of continuity of relationship & of knowing the individual. However, PC staff admitted to difficulties in these areas when providing care to PWID. Quality of care was affected in situations where staff failed to form authentic relationships.	A=3 B=2 C=2 **D=7**
Stein, 2008 [103]	To document the degree to which hospice & PC services were provided to New Jersey residents with an intellectual disability, and the challenges in providing this care	77	Questionnaire	Descriptive statistics & analysis for themes	22% of group home sponsors & 60% of developmental centres report ever using hospice services, with 1-2 residents using hospice care during the previous year. 91% of PC providers provided services to the community, with hospices providing care to approx. 3 individuals during the prior year. Challenges to providing services included: low levels of knowledge about PC among residential providers; need for knowledge about PWID among hospice providers; communication difficulties; & costs concerns regarding reimbursement, staffing, training.	A=1 B=2 C=2 **D=5**
Tuffrey-Wijne et al., 2017 [104]	To gain insight into the individual, organisational & contextual factors that affect the communication of death-related bad news to PWID by ID staff & to develop guidelines for services to enable appropriate communication with PWIDs about death and dying.	20	Semi-structured interviews	Framework analysis	Staff found supporting PWID around death & dying extremely difficult & tended to avoid communication about death. The following factors had a particularly strong influence on staff practice around communicating death-related bad news: fear & distress around death; life & work experience; and organisational culture. Staff attitudes to death communication had a stronger influence than their PWID's level of cognitive or communicative abilities. Managers were important role models.	A=2 B=2 C=2 **D=6**
Tuffrey-Wijne et al., 2016 [105]	To define consensus norms for PC of PWID in Europe.	80	Delphi study	Dephi study techniques	13 norms described: equity of access, communication, recognising the need for PC, assessment of total needs, symptom management, EOL decision making, involving those who matter, collaboration, support for family/carers,	A=2 B=2 C=2

					preparing for death, bereavement support, education/training & developing/managing services.	**D=6**
Tuffrey-Wijne et al., 2007 [106]	To investigate the issues and difficulties arising for PC staff in providing care for people with an intellectual disability.	32	Semi-structured interviews	Thematic analysis	Factors affecting PC provision for PWID included social issues (home situation & family issues), emotional & cognitive issues (fear, patient understanding, communication, cooperation & capacity to consent), problems with assessment, & the impact on staff & other patients. An underlying theme was the need to take more time and to build trust. Despite the challenges, many PC staff managed the care of PWID well.	A=3 B=2 C=2 **D=7**
Tuffrey-Wijne et al., 2010 [107]	To explore the experiences of PWID who have cancer (the Veronica Project)	13	Ethnography	Grounded theory	The main themes were dependent lives; deprived lives; truth telling and understanding; the importance of families; inexperienced carers and unprepared services; & resilience.	A=3 B=3 C=2 **D=8**
Tuffrey-Wijne et al., 2009 [33]	To explore the experiences of PWID who have cancer (the Veronica Project)	13	Ethnography	Grounded theory	Participants' cancer experiences were shaped by their previous experience of life, which included deprivation, loneliness, & a lack of autonomy & power. They depended on others to negotiate contact with the outside world, including the healthcare system. This could lead to delayed cancer diagnosis & a lack of treatment options. Most participants were not helped to understand their illness & its implications. Doctors did not assess capacity but relied on carers' opinions.	A=3 B=3 C=2 **D=8**
Tuffrey-Wijne et al., 2007 [108]	To elicit the views of PWID on end-of-life care provision	14	Focus groups using nominal group technique	Nominal group technique	Participants generated a mean of 9 individual responses. The highest rankings were given to issues around involvement in one's own care, presence of family & friends, offering activities to the ill person, & physical comfort measures.	A=3 B=3 C=2 **D=8**
Tuffrey-Wijne, 2009 [109]	To explore the experiences of PWID who have cancer (the Veronica Project)	13	Ethnography	Grounded theory	A good place of care, and ultimately a good death, required the following components: 1. Familiar or safe surroundings with familiar people. What seemed important was that people were in a place where their physical needs could be met and close bonds with family, friends and carers could continue until the moment of death & beyond. Continuing close bonds was easiest at home but could also be achieved elsewhere. 2. Freedom from pain and anxiety. In almost all cases, this required input from specialists, such as the PC teams 3. The closest carers needed extensive support from their managers and/or outside professionals; information on know what was happening and what to expect; they also needed recognition and support for their grief.	A=3 B=3 C=2 **D=8**
Tuffrey-Wijne, 2002 [110]	To consider the unique needs of a PWID who has intellectual disabilities and a terminal illness.	7	Case study	Category analysis	5 broad sets of themes emerged- difficulties & delays around diagnosing the illness, consent issues, conflicts between the carers and the family, truth-telling, & the need for professional support.	A=2 B=2 C=2 **D=6**
Voss et al., 2020 [111]	To find out what is important for ACP in the palliative phase of PWID.	20	In-depth interview	Thematic analysis	Important themes in ACP were as follows: tailoring care, working as a team & taking & giving time. The perceived role of PWID in ACP was to express their wishes. Relatives had a signalling, representing & contributing role. HSCPs felt their role was to inform, collaborate & coordinate.	A=3 B=2 C=1 **D=6**

Voss et al., 2021 [112]	To explore health practitioners' perspectives & practices relating to EOL decision-making & planning for PWID.	7	In-depth interview	Thematic analysis	4 main themes emerged: limited participation, bias, dignity, & quality of death. PWID are frequently excluded from decision-making related to EOLC. Participants discussed reasons including challenges with communication & cognition. Participants reported a need for additional support & guidance in providing care for PWID at the EOL. Professional & family bias played a role in EOLC decision-making for people with PWID. Participants reported a disproportional focus by PC practitioners on physical as opposed to emotional & spiritual well-being for patients with PWID at EOLC. Participants reported that PWID generally did not die in SPC, but in segregated supported living.	A=3 B=2 C=2 **D=7**
Wagemans et al., 2013 [113]	To clarify the process of EOL decision-making for PWID from the perspective of patient representatives.	16	Semi-structured interviews	Grounded Theory	The core category 'Deciding for someone else' describes the context in which patient representatives took EOL decisions. The patient representatives felt highly responsible for the outcomes. They had not involved the patients in the EOL decision-making process, nor any HSCPs other than the doctor. The categories of 'Motives' & 'Support' were connected to the core category of 'Deciding for someone else'. 'Motives' refers to the patient representatives' ideas about quality of life, prevention from suffering, patients who cannot understand the burden of interventions & emotional reasons reported by patient representatives. 'Support' refers to the support that patient representatives wanted the doctors to give to them in the decision-making process.	A=3 B=2 C=2 **D=7**
Wagemans et al., 2015 [114]	To clarify the process of end-of-life decision making relating to the care of PWID from the perspective of nurses.	9	Semi-structured interviews	Grounded theory	ID Nurses felt that they were at the centre of communication & were able to shape EOLC & influence EOL decisions. As they often had known & cared for the PWID for more than a decade, they had clear ideas about the patient's needs & preferences & showed confidence in their own opinion. Above all, they felt responsible for a well-managed end-of-life process. Tensions emerged when the views on quality of life differed between relatives & nurses.	A=3 B=2 C=2 **D=7**
Wallace, 2021 [115]	To provide a case study that describes the care of an adult with ID with a serious illness warranting PC, & focusses on the reasonable adjustments to mainstream core PC principles for PWID	1	Case study	Case study methodology	The essential nature of taking time for purposeful planning with disability professionals for the benefit of the patient & family unit is clear. The additional needs to engage with PWID & their families to appreciate properly the meaning of person-centred PC for them, to enhance inter-sectorial relationships in order to facilitate cross-fertilisation of PC & ID values, skills, knowledge & problem-solving ability of regulatory sector barriers remain essential.	A=2 B=2 C=2 **D=6**
Wark et al., 2022 [116]	To examine EOLC provision in rural areas in Australia.	22	Focus groups	Thematic analysis	Three thematic categories identified: availability of services; individual needs; & untreated pain. Specifically, participants noted concerns about the unavailability of health services, inflexibility of funding support, artificial government barriers, & a widespread lack of pain relief for individuals.	A=2 B=2 C=2 **D=6**
Watchman, 2005 [117]	To explore how issues relating to the end-of-life care for PWID & dementia affect practitioners & to assess the findings in relation to the existing research literature	10	Semi-structured interviews	Not described	Key among the findings were the need for people with Down syndrome to be more involved in planning for their own EOLC; a lack of communication between those persons working in PC & ID settings; identification of a "care culture clash;" deficits in training programmes for staff involving dying, death, & bereavement; signs that could identify pain & distress in PWID were not routinely available to staff. Procedures or guidelines were not in place for working with someone who was dying. The study revealed that PWID & dementia were not routinely asked where they wanted to die when confronted with EOL or were not given appropriate information to make informed choices.	A=1 B=2 C=2 **D=5**

Wiese et al., 2014 [118]	To explore what community living staff talked about & did with PWID) to assist them to understand dying & death.	22	Focus groups and individual interviews	Grounded theory	There was little evidence that staff talked with or did things with clients to assist understanding of the EOL, both prior to & after a death. Prior to death staff assisted clients in a limited way to understand about determining wishes in preparation for death, & what dying looks like by observation of its passage. Following a death staff offered limited assistance to understand the immutability of death, & how the dead can be honoured with ritual, & remembered.	A=3 B=3 C=2 **D=8**
Wiese et al., 2012 [119]	To explore the current status of EOL care & dying of PWID based on the experiences of staff in community living services.	33	Focus groups and individual interviews	Grounded theory	The current status of EOL care & dying comprised five 'issues': knowledge of dying, ethical values, the where of caring, the how of caring & post-death caring. These issues occurred in relationship with 'partners', including the dying person, other PWIDs, fellow staff, family, external health services & the coroner	A=3 B=3 C=2 **D=8**
Wiese et al., 2013 [120]	To explore the way in which community living staff engaged with PWID about dying and death.	33	Focus groups and individual interviews	Grounded theory	While in principle, staff unanimously supported the belief that PWID should know about dying, there was limited in-practice engagement with PWIDs about the topic. Engagement varied according to staff experience, PWID capacity to understand and the nature of the 'opportunity' to engage. Four 'opportunities' were identified: 'when family die', 'incidental opportunities', 'when PWIDs live with someone who is dying' and 'when a PWID is dying'. Despite limited engagement by staff, PWID are regularly exposed to dying & death.	A=3 B=3 C=2 **D=8**

Table 6 Palliative care needs and complexity[6]

Author, year	PC needs	Complexity
Bailey et al., 2016 [36]	PWID: end-of-life care, pain & symptom control; personal care including pressure relief & skin care; nutrition management Family: information and support Staff: information and support	Complexity lessened by- family cooperation & understanding; recognition that family know the person best; openness of family to develop a working relationship with HCP. Complexity heightened by- lack of cooperation from family; uncertainty causing over-protective family. Complexity lessened by- experience working with PWID, development of understanding & skills. Barriers- Limited education; lack of understanding & lack knowledge of ID. Complexity lessened by- support for team; collaboration, co-ordination & co-operation between all staff. Barriers- absence of critical team members; poor decision-making processes in organisations & family/s Complexity lessened by- ID staff recognition & acceptance of the need for PC support; willingness of ID staff to share knowledge to support SPC. Barriers- delay in recognition of transition to EOL; delay in referral to SPC. Complexity lessened by- knowledge of services available & how to access, listening, communicating, advising, kindness, awareness, honesty, caring, understanding, sincerity. Barriers- Fear due to lack of knowledge, education & experience; Lack of confidence in communicating with PWID Complexity lessened by- recognising resources – long term carers; having time & building a relationship & sharing the journey; building trust of client & family; early referral & advance planning. Barriers- poor information; delayed referral & lack of advanced planning; interpreting communication differences of PWID.
Bekkema et al., 2014 [77]	PWID: information needs; family & staff need for guidance in how to approach this; physical care needs; comfort; help PWID adjust/ adapt to new situation & re-establish/ maintain a level of familiarity & safety Family: support for family who assume burden of responsibility for making decisions	Complexity impacted by lack of experience of family & staff in managing/ encountering situations of communication towards EOLC with PWID. Complexity impacted by lack of ID staff skills in nursing & personal care; normal desire/ behaviour to respect & promote independence & autonomy Complexity impacted by communication difficulties; lack of prior expression of wishes/ values. Complexity impacted when wishes of the PWID conflict with opinion of the family/ team & they are concerned that the person is not making a decision in their best interests due to the impact of impairment on decision-making process. Balancing respect for decision-making with 'unwise' decisions. Complexity impacted by conflict between respecting wishes & providing high quality care (additional complicating layer when differing opinions about what constitutes quality care or differing opinions about ability of team members to provide care). Complexity impacted by 'knowing' individual helps quality of communication & interpretation of wishes & support of autonomy. PWID can adapt/ change with time in response to illness & circumstances- this may surprise caregivers.
Bekkema et al., 2015 [78]	PWID: physical and personal care; pain & symptom relief; emotional needs of staff (grief & loss while managing professional responsibilities); emotional needs of family; decision-making, particularly decisions relating to EOLC	Complexity impacted by balancing the tension between usual practice of promoting autonomy & independence & managing deterioration & changing goals of care- 'being there', making more time to be available & being responsive to individuals needs identified as facilitators to transition. Complexity impacted by recognising and managing symptoms particularly complex when PWID unable to communicate. Factors that alleviated complexity when dealing with complexity in symptom management: 1) 'attentiveness' to the person's signals and expressions of needs, distress, and pain, often best done by permanent care staff and relatives who had a life-long relationship with the person, and 2) 'openness to cooperation and building a shared understanding' of the interpretation of signals and expressions. Factors that alleviated complexity when dealing with decision-making: 1) 'responsibility' for taking joint decisions in the best interests of the person, 2) 'attentiveness' to the person's wishes, 3) relatives' 'reflection' on their own emotions, and 4) 'openness to cooperation and making shared decisions'. Complexity magnified by need to manage relationship between 'two families' of staff and relatives. 'Openness

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[6] PWID: people with an intellectual disability; ID: intellectual disability; PC: palliative care; SPC: specialist palliative care

		to cooperation and sharing' the care facilitated management of this complexity. Support of staff, reflective practice and the nature of the caring relationship all help complexity.
Bekkema et al., 2016 [79]	PWID: physical and personal care; pain & symptom relief; emotional needs including quality of life & support & desire to be at peace in final stage of life; need to be involved in decision-making & have wishes respected, including funeral; psychosocial needs; spiritual needs	Complexity impacted when PWID have difficulty communicating wishes & require support of others to communicate, record, or have wishes acted on- particularly challenging for those with more severe disability or communication impairment.
Brown et al., 2003 [80]	PWID: pain and symptom control needs; communication needs; spiritual needs; psychosocial needs; emotional & support needs of family; needs of peers; needs of staff- practical, emotional; decision-making- about treatment, care plan, disclosure.	Complexity lessened when MDT works effectively; when information is available to assist in decision-making, when staff are provided skills/ education and support. Complexity heightened when disagreement between team & family e.g., disclosure or when needs of family are intense. Complexity affected by trajectory of illness e.g., prolonged uncertainty challenging or if time spent in hospital- added to staff demands on time etc., communication challenging Perception of complexity appeared influenced by ultimate outcome e.g., if a good death achieved, or if staff member left with feelings of guilt.
Bycroft, 1994 [81]	Pain & symptom management; wound care; education & training support needs of staff; Decision-making regarding treatment in setting of impaired capacity; physical, social & spiritual needs.	Staff lack of training & education heightened complexity (affecting PC & ID staff); lack of time/ resources heightened complexity. Training & support; effective MDT working & collaboration between PC & ID services that built a trusting relationship; reflective practice; are all of help Effective communication & care planning between team & family of value. Time to develop relationship between PC staff & PWID which facilitates communication & recognition of distress.
Cartlidge and Read, 2010 [82]	Pain and symptom management; communication; family support	Complexity affected by the following characteristics of the person with an intellectual disability: communication ability, social skills, ability to understand information & participate in decision making. Complexity affected by the following characteristics of the family: engagement with team Complexity affected by the following characteristics of the team collaboration, staff skills, experience, staff attitudes & perceptions 'Knowing' the individual, additional time requirements and challenging behaviour all impact also.
Cithambaram et al., 2020 [83]	PWID: information & communication; decision-making; emotional support Family: information & communication; decision-making; emotional support	Complexity heightened by families who adopt a paternalistic approach when this is not desired by patient/ staff or when opinion of family is at odds with that of patient/ staff; collusion. Complexity heightened when autonomy of PWID not respected Complexity reduced by advance care planning, proactive approach to planning; when clear, person-centred information easily available and when PWID are informed and involved in care (as this lowers their anxiety and overall causes 'less tension and confusion'). Also, important to maintain communication with families to support their engagement. Complexity reduced when family able to support PWID.
Cithambaram et al., 2021 [84]	PWID: personal care & support; physical comfort; emotional needs; spiritual needs; communication, information provision and engagement in decision-making; psychosocial support; safety; life resolution Family: emotional needs; communication & information provision; engagement in decision-making; peers: emotional needs; communication	Complexity reduced by communication, information provision; adequate resources & time; maintenance of social networks & supports; holistic, person-centred care including attention to spiritual supports, companionship & creating an environment of safety.
Foo et al., 2021 [85]	PWID: communication & information provision; engagement in decision-making; time & therapeutic relationship	Complexity affected by the characteristics of the person with an intellectual disability: communication impairment; ability to make or express decisions; ability to start of initiate conversations. Complexity affected by the characteristics of the family: family beliefs, wishes, preferences. Complexity affected by the characteristics of staff: experience (extensive or limited), skills, training, values (equity, protectionism)

		Complexity affected by effective collaboration between those familiar or experienced with the individual. Complexity affected by time to build relationship; knowing the individual (rapport and relationship); culture of equity, promotion of autonomy.
Forbat and Pekala, 2005 [86]	PWID: pain & symptom control; nutrition & hydration; familiarity & continuity Peers: needs of peers who are affected by the illness of the person with an intellectual disability	Management ideals, broad cultural influences, religious ideology, individual episodes, even historical precedent ('we always do it this way and it has worked'); characteristics of the PWID personal characteristics of staff; resources; family & staff relationships and beliefs.
Gray and Kim, 2020 [87]	Support needs of staff- both emotional and practical over course of illness and during bereavement	Complexity heightened by lack of preparation- important that management communicate with staff about PWID condition/ prognosis (both practical & emotional aspects of care) Complexity could be variably heightened or lowered by close relationship between PWID & staff- particularly when viewed as family or when staff themselves lack family. Lowered when viewed through the lens that attachment is inevitable but also a normal part of life, and loss is a normal part of life, so better to be aware and open to same. Complexity of grief reaction helped by example of PWID & their resilience, & living in the moment, & having a sense that one did the best one could. Also support of other team members (informal) and professional grief counsellor, bereavement support groups, time to reminisce and mourn at work (adjust workload and give time/ space to staff) & opportunity to attend funeral if desired.
Hussain et al., 2019 [88]	PWID: Communication, decision-making, psychosocial Peers: emotional, management of loss, grief, bereavement Family needs: communication, decision-making, emotional support Staff: emotional & practical	PWID: maintenance of relationships affected by moves/ geographical distance; Family: prior history of loss, geographical proximity/ distance, relationships with staff, tension over who is 'perceived to know the PWID best/ know what is best for them' Staff: family relationships; continuity; place of care; peers; staff emotions; resources available; ability to maintain contact with PWID if their place of care changes; their opinion being valued Peers: prior experiences of loss; proactive preparation for loss; involvement and engagement with person; provision of supports including counselling; magnitude of decision-making at EOL Complexity affected by proactive preparation, engagement with families.
Kim and Gray, 2018 [89]	PWID: physical, personal care needs, emotional. Peers: emotional, management of loss. Staff: emotion and practical/ knowledge	PWID: Complexity affected by person-centred care, responding with empathy Staff: Complexity affected by education, training, skills including recognition of need to adapt care, focus on the moment; resources including time; team working; communication & information provision; staff emotional response, anxiety experienced in anticipation of dying phase; uncertainty regarding prognostication; lack of knowledge regarding hospice
Kirkendall and Waldrop, 2013 [90]	PWID needs: physical, emotional, psychosocial, familiarity; Needs of peers: support; Needs of staff: emotional support, practical/ knowledge needs	Complexity affected by the following characteristics of PWID: communication ability of PWID; staff member having a relationship with PWID of value being able to maintain continuity/ familiar routine Complexity affected by the following characteristics of staff: having information; team working, partnership with SPC, providing person-centred care; adequate resources, support.
Li and Ng, 2008 [91]	PWID needs: physical, emotional, psychosocial, spiritual.	Complexity affected by availability of Information; team working
Lindop and Read, 2000 [92]	PWID: pain and symptom control; communication.	Complexity affected by communication ability of the PWID; staff skills, education & training; availability of information.
McCarron et al., 2010 [93]	PWID: Pain & symptom management; communication including the provision of information; psychosocial needs; emotional needs; spiritual needs; peaceful environment Decision-making; advance care planning Family communication, information provision, decision-making and support Staff support and training	Complexity addressed when patient is at the centre of concern; quality care, comfort and spiritual support are attended to; & services are delivered in an environment that is capable, peaceful, and supportive. For many, small community settings where people had always lived seemed the optimal setting. Good care also included support and adequate resources for peers, family, and staff. The commitment of many participants to sustaining the person where they have always lived was challenged by their concerns for the potential of negative impacts on peers in that setting. The participants recognized that coordination of care across service systems was also needed. Lack of experienced staff (including medical decision-making). Lack of team working across and with hospital; knowing the individual; team meetings; family meetings; family ability to understand information. Ethics committee to support decision-making.

McCarron et al., 2011 [37]	PWID: pain & symptom management; personal care needs including skin care; communication including the provision of information to family; psychosocial needs of PWID; emotional needs of PWID; spiritual needs of PWID; peaceful environment; decision-making and management of ethical issues including feeding (PEG); advance care planning; Staff support & training	Complexity reduced by proactive approach to care planning and involvement in SPC in care planning (different & complementary perspective); SPC support perceived to provide reassurance to ID team; good team working (including clarity regarding roles/ responsibilities and alleviation of the burden of having to make decisions alone); availability of information; staff training & skills; adequate resources & time for care provision- particularly in the dying stage. Complexity heightened by hospital admissions and what is perceived as poor care (skin care/ personal care), poor decision-making (PG placement).
McCarron et al, 2010 [94]	PWID: pain and symptom control; personal care needs; decision-making including nutrition & hydration; Needs of peers; Needs of staff	Complexity affected by availability of resources; individual needs of PWID; needs of peers; physical environment; magnitude/ emotional impact of ethical issues such as nutrition; partnership working with SPC services.
McKibben et al., 2020 [30]	Information about illness, supports, pain control; how to provide personal care & use equipment; communication, engagement in decision-making; care planning; practical & emotional support for families	Complexity increased when information not provided or provided poorly due to suboptimal communication; when team not functioning properly; when team don't have information e.g. on services available; when crises/ emergency situations happen & there isn't a plan in place; when partnership working between ID & SPC not established; when family are perceived as not having the knowledge/ experience to make decisions on issues such as DNAR or when emotion is 'clouding' decision-making; when paternalistic culture in place that doesn't respect autonomy of PWID; individual attributes of staff aren't conducive to communication Complexity lessened when team take lead from family who 'know' PWID; when information available; when working relationships established; when care planning done in advance.
McLaughlin et al., 2015 [95]	PWID: Physical, communication, emotional, personal, spiritual needs; familiarity Family: information and support	Complexity affected by characteristics of person, family characteristics- wishes, resilience, experiences; time; resources; MDT availability and working; information including on prognostication; partnership working- knowledge of service availability for PWID and their families
McNamara et al., 2020 [96]	PWID: pain & symptom control; dignity; emotional; psychosocial; Peers; familiarity; communication; decision-making; Staff educational needs.	Complexity affected by the following characteristics of PWID: communication ability; decision-making capability Complexity affected by the following characteristics of family- involvement in decision-making, wishes, preferences; culture Complexity affected by the following characteristics of staff- skills of staff; information provision; effective team working; person-centred care. Complexity affected by the following characteristics of peers: needs of other residents & impact of this on person with illness Complexity affected by the following characteristics: diagnostic overshadowing; life of loss, change; culture of promotion of autonomy/ support; 'hidden' nature of disability
Ng, 2003 [97]	PWID: pain and symptom control; communication; psychosocial care; wound care. Emotional support for family & significant others. Culturally appropriate care of the dying	Complexity affected by the following characteristics: lack of training/ skills in pain and symptom control; communication; care of the dying person.
O'Sullivan and Harding, 2017 [98]	Care of dying patients; emotional needs of family; emotional needs of peers; emotional needs of staff	Complexity affected by the following characteristics: Partnership working between services; adequate resources & support from management including support of loss & grief; collaboration with family; education & training; proactive preparation; development of resources such as policies/ guidelines.
Rauf and Bashir, 2021 [99]	PWID: Personal care & support; physical comfort; emotional needs; spiritual needs; communication, information provision and engagement in decision-making; psychosocial support; Family: emotional needs; communication & information; appropriate engagement in decision-making	Complexity affected by the following characteristics- PWID: impaired ability to make or communicate decisions Complexity affected by the following characteristics- family: paternalistic approach; differing opinions between family members & staff regarding care plan Complexity affected by the following characteristics- ineffective team working; failure to implement best practice with regards to decision-making & care planning for PWID; availability of information
Read and Cartlidge, 2012 [100]	Personal & practical supports for the person with an intellectual disability & their family; emotional supports for family; educational & training supports for team.	Complexity affected by physical & emotional care needs of family; education & training for staff; effective team working & transparent/ best practice approach to supporting decision-making. Complexity lessened by proactive approach to care planning; person-centred care provision that respects autonomy & wishes of individual.

Ryan et al, 2011 [49]	Peers are emotionally impacted by illness/ loss of peer. Need for pro-active preparation & support. Requires time, resources, training of ID staff & openness of family members of both person with illness & families of peers to support.	Complexity affected by PWID characteristics- communication ability; awareness/ understanding of illness or death Complexity affected by the characteristics of family of person with an intellectual disability with life-limiting illness- openness to allowing involvement/ engagement of peers in illness journey and rituals e.g., funeral. Complexity affected by the characteristics of staff- SPC recognition of impact on peers & willingness to support as part of their role; ID staff- time and skills to support peers
Ryan et al, 2011 [101]	ID staff needs- recognition of relationship with PWID & emotional impact of the illness/ death on staff; emotional support to manage grief & adapt; time to provide care & mourn; emotional support to manage personal & ethical impact of advocacy & decision-making	Complexity heightened when PWID lack communication abilities or decision-making capacity to make wishes/ preferences known and staff assume responsibility for same. Complexity heightened by complex/ ambiguous legislative environment. Complexity heightened in situations of inadequate time to provide care or mourn loss. Complexity heightened in situations of strained relationships with families or when families become 're-involved' in care following period of absence or when families perceived as 'pushing out' staff.
Ryan et al, 2011 [102]	Communication- establishment of a trusting therapeutic relationship; information provision about illness, death and dying; managing collusion; management of truth-telling; management of gatekeeping; management of communication with family and between patient, family & carers. Pain & symptom management. Emotional support.	Complexity affected by the characteristics of PWID- communication ability; awareness/ understanding of illness or death; ability to pro-actively ask questions or indicate wishes about information provision. Complexity affected by the characteristics of family- gatekeeping or role family members play in supporting communication; family wishes or preferences Complexity affected by the characteristics of ID team- communication training/ skills/ experience in dealing with life-limiting illness; personal beliefs regarding truth-telling in illness and impact of information/ knowledge on PWID; fear of causing harm or emotional distress to PWID; MDT team working and relationships; skills/ confidence in determining level of understanding that PWID have regarding illness
Ryan et al, 2016 [31]	Symptom management; communication needs; decision-making regarding serious illness, death & dying; ensuring safe, secure, familiar environment; emotional support	Complexity heightened when staff do not have trusting relationship with PWID; when staff do not 'know' PWID; when PWID is not familiar with staff Complexity affected by the characteristics of SPC staff- when staff lack knowledge/ experience/ training in caring for PWID; when staff do not have adequate time to form a relationship; where communication impairment/ cognition impacts on the formation of the relationship Complexity affected by the characteristics of family- when family act as gatekeepers
Stein, 2008 [103]	Physical, personal, emotional, staff, peers, family; disability; decision-making.	Complexity affected by communication; family; resources; training/ skills of ID & SPC staff; partnership working/ awareness; decision-making capacity assessment
Tuffrey-Wijne et al., 2017 [104]	Comfort; staff support needs; communication	Complexity affected by: Characteristics of PWID; staff characteristics and training, skills, cultural background & life experiences; organisational supports & preparations- policies, debriefing, leadership, training & supports.
Tuffrey-Wijne et al., 2016 [105]	Pain and symptom management; emotional, psychosocial and spiritual of the person with an intellectual disability; needs of the family; needs of peers; needs of staff; decision-making; communication.	PWID, Complexity affected by communication ability; awareness/ understanding of illness or death; life experience & opportunity to learn about illness/ death; challenging behaviour; diagnostic understanding Complexity affected by family relationships & impact of illness on grief & loss Staff relationships & impact of grief & loss; time & resource availability Peer relationships & impact of grief and loss; increased vulnerability to complicated grief Complexity affected by magnitude of decision-making at EOL & legislative environment
Tuffrey-Wijne et al., 2007 [106]	Pain & symptom management; communication- information provision about illness, death & dying; communication about symptoms; decision-making and issues of consent and capacity; additional time required to develop relationship & provide care; impact of illness on family; cumulative complexity- increased vulnerability & needs due to illness; place of care; financial support; support for other team members	Complexity affected by characteristics of PWID: communication ability, emotional response, decision-making/ ability to understand illness; communication characteristics e.g. 'blunt' speaking; pain & symptom assessment Complexity heightened by change in environment/ loss of familiarity Complexity heightened by family coping, emotional response to illness, ability to understand information Complexity heightened by SPC & ID staff skills, experience, emotional response to illness Complexity heightened by additional time required to support individual, staff & family & to build trusting relationship with PWID; impact of behaviour of PWID on other patients in hospice environment. Complexity affected by SPC staff misperceptions regarding ID e.g., inability of person to engage because of ID & so no value in referring.
Tuffrey-Wijne et al., 2010 [107]	Pain & symptom management; communication- information provision about illness, death & dying;	Complexity affected by characteristics of PWID: communication impairment; difficulty making or expressing wishes/ decisions; life-long history of lack of respect for autonomy; prior history of loss; vulnerable to

	communication about symptoms; decision-making & issues of consent & capacity; additional time required to develop relationship and provide care; need for familiarity, safety & security; emotional needs; psychosocial needs; personal care needs; staff support needs in terms of care provision	mistreatment/ harm; Complexity affected by ID staff characteristics: lack of knowledge or experience in provision of PC; misperceptions (e.g. role of pain relief); Complexity affected by PC staff: lack of knowledge or experience in providing care to PWID, reduced ability to communicate or understand communication needs (e.g. acquiescence). Complexity affected by: late diagnosis; diagnostic overshadowing; family influence on decision-making; gatekeeping; over-protection
Tuffrey-Wijne et al., 2010 [33]	Pain & symptom management; communication-information provision about illness, death and dying; communication about symptoms; adequate resources to support care; emotional support; familiarity; support for staff- emotional, training & practical; support for family caregivers; psychosocial needs- limited support networks that are further reduced by illness. Impact of illness on peers- both emotional & practical.	Complexity affected by the characteristics of PWID- ability to communicate and participate in decision-making; prior history of loss or anxiety; Complexity affected by the characteristics and skills of staff including presence of staff misperceptions that may heighten complexity (forced jollity); characteristics of family including presence of misperceptions (lack of value of treatment). Impact of illness on peers and practical considerations regarding feasibility of place of care. Resilience of PWID helped management of complexity- they were “experienced sufferers” with lifelong training in coping with adversity; they were skilled at living in the present moment and “taking each day as it comes” ; commitment of staff; maintenance of routine/ familiarity; prior experience of dependency; they were used to being cared for, making the loss of power and control that often accompanies terminal cancer less shocking for them; the presence of one or two trusted carers , who knew them intimately and was present throughout the illness.
Tuffrey-Wijne et al., 2007 [108]	PC needs associated with physical illness (medical treatment, pain relief, food & drink, keeping warm), involvement (tell person what is going on, listen to his/her wishes), relationships (have family & friends around, phoning friends, comfort & touch), organising supporting care (help in the house, nursing presence, walk the dog, go to a nursing home), keeping active & occupied (work, outings, TV, magazines), atmosphere (lively, friendly, emotionally supportive) & preparation for death (organize the funeral, support the family, say goodbye).	Factors associated with complexity not specifically explored. Of note, findings suggest that many PWID base their answers on personal experience.
Tuffrey-Wijne, 2009 [109] PREFERRED	Pain & symptom management; communication-information provision about illness, death and dying; communication about symptoms; resources to support care; emotional support; familiarity; support for staff- emotional, training & practical	Complexity affected by the characteristics of PWID- ability to communicate and participate in decision-making; prior history of loss or anxiety; Complexity affected by the characteristics and skills of staff including presence of staff misperceptions that may heighten complexity (e.g., painkillers)
Tuffrey-Wijne, 2002 [110]	Communication- information provision about illness, death & dying; Pain & symptom management; personal care & nursing; Diagnostic overshadowing; Decision-making- balancing best interests & autonomy; Impact of illness on peers; Training needs of staff in provision of care; Impact of illness on family; managing relationships between team & family; balancing wishes/preferences of family & wishes/ preferences & best interests of client.	Complexity heightened when staff lack experience/ skills in either provision of palliative care or care for PWID; complexity heightened when prognosis uncertain and challenging to know what to plan for; when disagreement between family and team regarding care plan; when PWID unable to decide or express wishes/ preferences; when PWID aware of tension between family & team and try to please both; when staff do not understand impact of communication impairment/cognitive impairment on PWID e.g. less likely to ask questions/ proactively engage. Management of complexity helped by having engaged and supportive GP & primary care team; good team working; establishment of working relationship between team and family; when family trust team.
Voss et al., 2020 [111]	Decision making; communication	Complexity affected by: PWID communication ability; decision-making capability; individual preferences-emotions

		Complexity affected by family- involvement in decision-making, wishes, preferences Complexity affected by skills of staff; information provision; effective team working; person-centred care; trust; time; proactive approach; emotional support for families; adjustment; staff support
Voss et al., 2021 [112]	Physical, emotional, psychosocial, spiritual, familiarity, continuity, peers, family, staff, quality of life, communication, decision-making; needs of peers	Complexity heightened by characteristics of PWID- communication ability; decision-making capability Complexity heightened by characteristics of family- involvement in decision-making, biases, paternalistic approaches Complexity heightened by characteristics of organisational structure- including moving people to new facilities Complexity heightened according to characteristics of staff misperceptions, biases, skills, information, resources (including whether spiritual care available or not).
Wagemans et al., 2013 [113]	Pain and symptom relief, quality of life, emotional needs of PWID; Decision-making; Family communication, information provision & support	Complexity affected by the following characteristics: Lack of information provision to family; personal attributes of staff; skill of staff; effective collaboration/ team working; disagreement between family and staff; lack of clarity regarding roles/ responsibilities; lack of clarity regarding legislative environment/ requirements; time
Wagemans et al., 2015 [114]	Communication & information provision; decision-making engagement- PWID, families & staff; staff support- professional & emotional	Complexity affected by the following characteristics: when disagreement between family & staff; knowing' the individual; effective team working; staff experience, knowledge & skill; clarity regarding roles & responsibilities
Wallace, 2021 [115]	Pain & symptom management; communication including provision of information & decision-making Needs relating to presence of disability and chronic illness; Family communication & engagement in care planning & decision-making	Complexity affected by the following characteristics: Cumulative complexity; team working; need for time and knowing the individual Complexity affected by the following characteristics: Presence of prior illness & disability e.g., polypharmacy; multiple team members Organisational & practical consequences of living in an ID organisation (e.g. medications, resources, capability of staff)
Wark et al., 2022 [116]	Pain & symptom control; emotional support including mental health needs of person with an intellectual disability; need for sense of safety security; personal care needs	Complexity heightened when person with legal responsibility for making decisions (guardian) not familiar with the person with an intellectual disability; when location of care distant from hospital/ other team members. Complexity affected by communication ability of PWID; resources, time; changing needs over time & time required to access resources Complexity heightened when staff don't have knowledge/ skills e.g. pain relief but lessened by partnership working with SPC. Complexity lessened by proactive planning; maintaining the psychosocial network & activities of the PWID as far as possible; by HCPs practicing person-centred care where relationships formed with PWID (& vice versa); and by spending time with the person & providing relational care.
Watchman, 2005 [117]	Personal care needs; communication & decision-making; needs of peers; educational & training needs of staff; pain & symptom management.	Complexity affected by staff education & training & lack of understanding of disease trajectory; partnership working with SPC & lack of awareness of services; resources; impact on other PWID; dynamic nature of illness & time taken to put resources in place; lack of proactive planning; personal beliefs regarding issues such as PEGs; diagnostic overshadowing; managing the culture clash between enablement & palliation; managing different cultural beliefs/ expectations; lack of policies; lack of engagement with PWID regarding wishes & preferences.
Wiese et al., 2014 [118]	Needs of peers- information provision, emotional support Needs of person who is dying- emotional, spiritual- but appeared under-recognised and responded to in practice.	Complexity influenced by proactive preparation, staff engagement & willingness to provide EOLC; clear communication between management &staff; adequate time & resources to provide care; counselling, rituals, characteristics of PWID (cognition and emotions).
Wiese et al., 2012 [119]	Physical, personal care needs; emotional, communication, decision-making of PWID; needs of peers; staff needs	Complexity influenced by proactive preparation, engagement, staff, time, availability of resources, maintenance of familiarity; participation in rituals, characteristics of PWID (cognition & emotions) Complexity can be variably influenced by staff awareness/ understanding of needs of PWID & peers regarding EOLC; & also by understanding of their role e.g. whether or not to engage with a family regarding their decisions about truth-telling; organisational characteristics e.g. whether staff can give medications Perception of complexity appeared influenced by ultimate outcome e.g. if a good death achieved, or if staff member left with feelings of guilt.

Wiese et al., 2013 120	Needs of peers- information provision, emotional support	Complexity affected by the following characteristics: life experience, personal characteristics of PWID (including cognition & emotions), family, staff experience, skills & personal life experience. Client diagnosis of dementia.

2.5 Study sample

The final sample comprised 50 articles that related to 38 distinct research studies. Overall, 22 of the 50 articles (44%) had been published prior to 2013 (i.e., over ten years ago). [38, 49, 81, 82, 86, 92-94, 97, 100-103, 106-109, 119, 121-124] The selected articles had quantitative, qualitative or conceptual approaches and the final sample included papers with the following design: focus group (n= 14) [31, 37, 38, 49, 79, 87, 89-91, 94, 98, 102, 116, 125]; individual interview (n= 12) [83-85, 90, 96, 104, 106, 111, 112, 114, 117, 126]; case study or series (n= 9) [78, 81, 91, 99, 100, 110, 115, 121, 127]; mixed methods (n= 7) [82, 92, 95, 118-120, 128]; ethnography (n= 4) [107, 109, 122, 123]; survey (n= 3) [36, 97, 103]; Delphi (n= 1) [105] and theoretical (n =1) [86]. A variety of qualitative analytical approaches were utilised including grounded theory [83, 84, 90, 107, 109, 114, 118-120, 122, 123, 126], content analysis, [91, 92, 95] thematic analysis, [37, 85, 88, 89, 93, 98, 106, 111, 112, 128] framework analysis,[38, 49, 101, 102, 104] and nominal group technique. [108] The sample size of articles ranged from 1- 121 participants. Participants from two empirical studies comprised people with an intellectual disability only; [79, 108] three studies comprised people with an intellectual disability and their family members only; [83, 84, 95] one comprised family members only; [126] three comprised family members and healthcare professionals; [127] and seven comprised people with an intellectual disability, family members and healthcare professionals. [107, 109, 110, 121-123] The remainder comprised healthcare professionals only. The quality score ranged from 3-8, with an average of 6.4.

2.6 Analysis

A hybrid approach of qualitative methods of thematic analysis was utilised. [129] It incorporated both the data-driven inductive approach of Boyatzis [130] and the deductive a priori template of codes approach outlined by Crabtree and Miller. [131] This approach complemented the research questions by allowing the conceptual framework of complexity in palliative care described by Pask et al. [61] to be integral to the process of deductive thematic analysis while also permitting themes to emerge direct from the data using inductive coding.

2.7 Findings

2.7.1 Palliative care needs

The palliative care needs of people with an intellectual disability were reported as being:

1. Physical and personal care to ensure comfort and dignity. [79, 81, 83, 88, 90, 91, 93, 94, 96, 97, 105-107, 109, 112]
2. Psychosocial care to ensure quality of life, social connectedness, and personhood. [33, 79, 81, 83, 88, 90, 91, 93, 94, 96, 97, 105, 107, 108, 112]
3. Emotional care to ensure well-being and mental health. [33, 37, 49, 78, 79, 83, 91, 94-96, 99, 101, 102, 105, 107-109, 111, 112, 116, 118, 120, 127]
4. Spiritual care to ensure peace and support. [33, 79, 83, 95, 105, 108, 112, 118, 121]
5. Communication tailored to ability, preferences, and best interests. [31, 33, 37, 83, 85, 88, 92-94, 97, 99, 102, 104-107, 109-111, 117, 121, 127]
6. End-of-life decision-making individualised to preferences, wishes, values and best interests. [31, 33, 78, 83, 88, 93, 95, 96, 99, 101, 102, 105, 108-112, 114, 115, 117-119, 126, 128]
7. Time and continuity of care to ensure security and well-being. [31, 78, 81, 82, 85, 102, 108, 111, 115]
8. Ongoing attention to pre-existing needs related to impairment or the social consequences of impairment, tailored to the context of a life-limiting condition. [49, 82, 84, 96, 105, 106, 110, 115]

Further description of these needs is provided in Table 7.

In addition, the peers of people with an intellectual disability, their family and ID staff were all noted to be impacted by the illness experience of the person with intellectual disability and were reported as also experiencing palliative care needs:

9. The needs of the peers of people with an intellectual disability related to a need for emotional and psychosocial support to help them cope with the experience of their peer's illness, loss, and grief; communication and informational needs; and the practicalities of minimising disruption and impact of another person's illness on their routines and quality of life. [33, 83, 86, 88-91, 94, 96, 98, 101, 103, 107, 108, 110, 112, 117, 119, 121]
10. The needs of families related to communication and informational needs; clinical decision-making and care planning support needs; emotional and psychosocial support to help individuals cope with loss and grief and the responsibility of shared decision-making; and practical supports to help them manage the care needs of the person with an intellectual disability and life-limiting illness (e.g., financial, respite, carers, education, and training). [36, 78, 83, 95, 98, 101, 103, 106-108, 110-112, 114, 121, 128]
11. The needs of ID staff related to communication and informational needs; clinical decision-making and care planning support needs; emotional and psychosocial support to help

individuals cope with loss and grief and the responsibility of shared decision-making; and practical supports to help them manage the care needs of the person with an intellectual disability and life-limiting illness (e.g., education and training, additional staff and resources, time to provide care). [31, 33, 36, 37, 78, 79, 81-83, 85, 88, 89, 92, 95, 96, 101-104, 106-111, 114, 115, 117-121, 126, 127]

Table 7 Palliative care needs of people with an intellectual disability

Physical and personal care needs	The most common physical need described was pain management, but the full spectrum of symptom distress associated with malignant and non-malignant disease was recognised. This included a need for additional assistance with personal care, skin care and activities of daily living. It was noted that people with an intellectual disability commonly express distress atypically, for example, through signs or behaviours such as altered movement or irritability.
Psychosocial needs	Psychosocial needs encompassed a need for human connection, friendship, and family support. People with an intellectual disability often had more limited social networks than the general population and were dependent on others to support maintenance of networks. The development of illness could have a profound effect on relationships and could result in isolation and loneliness. The legacy of institutionalisation meant that many had experienced separations from their families. Relationships with ID staff were generally long and close attachments that were often formed that some described as being analogous to 'family'.
Emotional needs	Emotional needs related to the impact of a life-limiting condition on emotional well-being. The experience of being unwell is one that can lead to mood disturbances such as anxiety or depression. People with an intellectual disability have higher incidences of mental health disorders and are more vulnerable to psychological trauma than the general population due to limited emotional regulation skills and cognitive challenges among other factors. [132] The development of a serious illness represented a further stressor to emotional wellbeing.
Spiritual needs	Spiritual needs were most often expressed as the need to achieve an inner 'peace', but the importance of faith as a source of hope, of 'connection', and of comfort was also observed. Spiritual needs could also relate to a need for closure and resolution of disagreement. Formal religious practice was the most common medium through which spiritual needs were met and this included attendance at church, praying and engagement with pastoral care.
Communication needs	Communication needs related to the universal human need to be heard and understood, to receive information and to participate in decision-making. However, the presence of impairments of cognition or communication meant that communication had to be tailored to individual abilities and circumstances. Carers frequently felt that they lacked the capability to either judge or respond to the communication needs of people with an intellectual disability in the palliative care setting. Often people with an intellectual disability lived in closed communication environments. This could result in further constraints being placed on autonomy or heightened emotional distress. It also could impact on an individual's physical comfort as signs of distress were overlooked or misinterpreted, and carers' responses were compromised.
End-of-life decision making needs	Clinical decisions made towards the end-of-life can be among the most challenging decisions to make. Decision-making in the context of intellectual disabilities is often complicated by challenges in assessing capacity, promoting autonomy, managing collusion, and determining best interests. Family and staff can feel inadequately prepared and supported to carry the moral and emotional burden of acting as decision-makers. The wishes, values, and preferences of people with an intellectual disability appear to be often 'hidden' or overlooked, and people with an intellectual disability are commonly not involved in end-of-life decision making even when they have the capacity to participate.
Time and continuity of care needs	Time is often required for people with an intellectual disability to build relationships with carers and for carers to truly 'know' the person. The quality of care provided to people with an intellectual disability is felt to be better when provided by carers who have an in-depth knowledge of the individual. People with an intellectual disability often find change difficult and distressing and their quality of life is negatively impacted when their place of care changes or when continuity of care is interrupted. The development of a life-limiting illness leads to some inevitable changes in personal circumstances (e.g., body changes, emotional

	responses) and the maintenance of routine, familiar surroundings and familiar people are felt to be important supporting mechanisms at a difficult time in life.
Pre-existing needs relating to the presence of impairment or the social consequences of impairment	A person with intellectual disability has certain limitations in cognitive functioning and skills, including communication, social and self-care skills which often give rise to the need for reasonable adaptations or increased supports. Some will have complex needs that require specialist support. Pre-existing needs do not 'disappear' when the person becomes unwell. In fact, they may sometimes become more acute. Traditional structure and organisation of services can pose barriers to the collaborative working that is required of a range of disciplines and services to adequately meet needs. The further development of integrated care is required.

2.7.2 Complexity

Palliative care provides care and support not only for the person with serious illness, but also for those important to them. As the literature review reveals, the 'unit of care' when providing care to a person with intellectual disability should extend to family, ID staff and peers because they all experience a variety of palliative care needs.

According to Bronfenbrenner's model, each individual person has one ecosystem, defined from the perspective of that person. [62-64] Pictorial representation of the individual's ecosystem is traditionally provided as a series of concentric rings, with the individual in the centre. However, the framework can also be used to consider the shared and overlapping ecosystems of any social network, such as are seen in palliative care provision for people with intellectual disability. This integrative review adopts the perspective of the shared network (termed the "Intellectual Disability Palliative Care network" or "ID PC network") in its consideration of complexity. Analysis relating to the ontosystem is presented in depth from the perspective of the person with intellectual disability and serious illness, given that the primary focus of care is on the person with the life-limiting condition. Analysis relating to other ontosystems is summarised in Table 8.

The ontosystem: the person with intellectual disability's biological, physical, mental, and emotional characteristics and relationships and interactions with the immediate environment.

The ontosystem refers to the person with intellectual disability as an individual, and focuses on the person's innate or acquired physical, emotional, intellectual, and behavioural characteristics. The following ontosystem themes were identified as key elements influencing the development of complexity experienced by the person with an intellectual disability: ***intellectual impairment;*** [33, 36, 91, 96, 107, 110, 117] ***communication impairment;*** [31, 33, 78, 79, 82, 85, 92, 95, 97, 99, 101-103, 105, 107, 109-112, 115, 120, 127] ***physical disability and functional decline;*** [33, 83, 96 78, 89, 98, 100, 117, 127] ***chronic illness;*** [102, 105] ***mental health and challenging behaviour;*** [82, 96, 105, 107] ***experience of a life of loss.*** [33, 83, 87, 88, 96, 100, 101, 107, 110] The ontosystem themes aligned with Pask's description of 'pre-existing complexity' where it was observed that the person's life already had qualities of complexity as a result of these factors before receiving palliative care. [61] The interaction of these factors with a life-limiting condition then often further magnifies complexity of need.

Level of intellectual impairment; communication impairment

Level of intellectual and communication impairment were considered to influence complexity because more severe impairment was universally regarded as acting as a barrier to expression of needs, understanding of condition and decision-making. When a person is unable to verbally communicate their needs, symptoms can intensify or an illness advance before carers realise something is wrong. Moreover, when a person has a communication impairment, it can be difficult to judge how much they understand about their condition and what their informational needs are. In such situations, carers find it difficult to assess whether a person does not want to talk, does not understand the concept of illness and death, or lacks the linguistic skills to converse. When a person does not understand what is happening to them, their feelings of anxiety and fear are difficult to address and an escalating cycle of total pain can develop. [33, 78, 81, 102, 105, 106, 112]

Physical disability and functional decline

Pre-existing physical disability and functional decline influenced complexity because the impact of a life-limiting condition on a person with a relatively poor level of baseline functioning was significant. Often resulting care needs were considerable and the functional loss that the person experienced was felt acutely by family or staff who had worked so hard with the person with intellectual disability to achieve their full potential. For individuals with significant dependency on others, any degree of functional loss could result in complete dependency and loss of autonomy. The challenge of managing the transition between promotion of autonomy for autonomy's own sake, and in recognising the changing nature of personhood in the face of advancing illness was commonly observed.

Mental health and challenging behaviour

Mental health and challenging behaviour were thought to be important features that impacted on the way that the person with intellectual disability reacted to the emotional stresses associated with serious illness. Pre-existing mental health disorders or challenging behaviour were perceived as resulting in an increased complexity of emotional need being experienced by the individual following the diagnosis of a life-limiting condition. Some care environments (such as a hospice or hospital) were viewed as places where it was difficult to care for people with challenging behaviour because of the lack of trained staff, the physical set-up of the spaces and the impact on other patients. [82, 106] The presence of emotional distress or challenging behaviour could also lead to diagnostic overshadowing where staff overlooked underlying physical illness or distress.

Chronic illness

The theme of chronic illness was one that had the potential to both heighten and reduce complexity. The presence of chronic illness was in itself associated with pre-existing complexity; the development of a life-limiting condition heightened complexity further because of issues such as management of polypharmacy, difficulty in differentiating between conditions and developing appropriate management plans, and the challenges of effectively coordinating care. Some participants felt that the experience of chronic illness might make it more difficult for people with impaired cognition to understand that they now had a life-limiting condition because they were used to continuously feeling unwell. However, the experience of chronic illness was also one that was felt to foster resilience and this was felt to have value in the setting of terminal illness. It was noted that the resilience demonstrated by people with an intellectual disability often acted as an inspiration and support for staff.

Experience of a life of loss

The theme of 'a life of loss' was one that many ID staff were acutely aware of. People with an intellectual disability were often felt to have dealt with adversity and trauma since birth. Staff spoke of abuse that people with intellectual disability experienced, including bullying and the use of chemical or physical restraints. They spoke of loss, such as the loss of families and home place, institutionalisation and the loss of staff and peers due to changes in living circumstances and staff turnover. Disenfranchised grief could further complicate issues. The impact of such losses were felt to be long-lasting, to increase vulnerability and to influence reactions to the development of a life-limiting condition. However, in a similar manner to the experience of living with chronic illness, it was also noted that people with intellectual disability had developed coping skills such as 'living in the moment' and had life-long training in adversity. [107] This could act as a counter-balance to the effect of past trauma.

2.9 The microsystem: time to allow a relationship to develop, 'knowing' the person with intellectual disability, maintaining normality.

The microsystem refers to the person of interest's immediate environment, and contains the relations between the person with intellectual disability and that environment. Home, hospital and hospice were microsystems commonly observed. However, 'home' comprised a variety of different environments, e.g., 'family homes', community-based residential care, and institutional settings. The following themes were identified as key elements of microsystems influencing complexity of need: **time to allow a relationship to develop,** [31, 36, 82, 85, 102, 106] **'knowing' the**

person with an intellectual disability, [36, 82, 85, 91, 96, 101, 106, 111, 121, 127, 128] **maintaining normality.** [37, 82, 90, 91, 103, 105, 110, 117, 121 86 78, 88, 101, 119]

Time to allow a relationship to develop

The time given to establishing a relationship between a person with intellectual disability and their carer was felt to be an important variable influencing the quality of that relationship. Time allowed repeated staff-client interactions to occur and for relationships to be formed. While members of the general population can forge relationships over short period, time was felt to be an essential element required to build connections with people with an intellectual disability. Care was more complicated when carers did not have create meaningful relationships with people with an intellectual disability.

‘Knowing’ the person with an intellectual disability

The second theme of ‘knowing’ was closely related to that of ‘time’. Repeated contact does not by itself does not lead knowledge of a person. A high-quality relationship between client and staff is also needed to develop understanding. [132] ‘Knowing’ the person with intellectual disability, therefore, inevitably has a personal dimension of particular relevance in the palliative care setting. ‘Knowing’ the person with an intellectual disability was a variable that influenced complexity in a number of ways.

It most often conferred benefit because it was by ‘knowing’ someone that individual communication patterns, responses and behaviours could be best interpreted. Although ‘knowing’ the person with an intellectual disability most often allowed carers to recognise changes from baseline early and thus alleviate complexity, sometimes situations could arise where carers were felt to become ‘complacent’ at their level of knowledge and to miss distress cues that might otherwise be evident. [96]

Significant weight was placed on the opinion of the carer who knew the individual with an intellectual disability well. This person could be a family member or a formal caregiver. The person often acted or was placed in the role of gatekeeper and mediator. Decisions about what or how much information to provide the person with intellectual disability with were usually made with the input of the person who ‘knows the individual best’. Care planning decisions were also heavily reliant on similar input. Communication was often managed through a three-way system that was routed through that person, rather than other people communicating directly with the person with intellectual disability. While the input of knowledgeable individuals was felt to be of vital assistance, carers (particularly specialist palliative care staff) who did not know the person with intellectual disability in the same way commented that nonetheless situations often remained complex. This was because the 'less knowledgeable' carers did not feel able to function at their usual level of expert practice and to make meaningful contributions to care. Also, situations commonly arose where the person who 'knows best' adopted a paternalistic or protective stance which resulted in closed communication practices and/ or collusion.

While the two themes of 'time' and 'knowledge' were identified as key elements affecting the complexity of palliative care need experienced by the person with an intellectual disability, the themes also represented elements that impacted on the complexity of ID staff need. This was because as part of the process of 'knowing' the individual over time, an emotional bond was usually formed. While the bond was often a source of comfort and strength to carers, it also heightened the experience of loss over the illness journey.

Maintaining normality

A third microsystem theme that was identified as key to affecting complexity was that of 'maintaining normality'. It was generally felt that people with an intellectual disability experienced change as disruptive and traumatic and that it resulted in loss of a sense of security and wellbeing. Changes in place of care were avoided wherever possible as it was felt that moves could precipitate a decline in skills, cause emotional upset from living in an unfamiliar environment and pose difficulties in maintaining relationships (friendships and relatives) if the new location was not very accessible. For these reasons, participants emphasised the need for maintenance of familiarity and continuity of care as a particular need that is experienced by people with an intellectual disability over the life-course, but particularly in the palliative care setting. When normality and the daily rhythm of life could be maintained, the complexity of palliative care needs such as psychosocial distress was lessened. The effect of 'maintaining normality' was not only important to the person with an intellectual disability; ID staff placed significant value on ensuring that routines and place of care were maintained as they felt that this reduced the distress of the person with an intellectual disability. They spoke of feelings of guilt, strain and sadness when they were not able to achieve this. [78, 88, 101, 119]

Cumulative complexity

In keeping with Pask et al.'s finding, it was observed that the number of problems encountered and whether problems were experienced across several or all domains of need magnified complexity. [61] The concept of 'cumulative complexity' was therefore felt to be applicable to the care of the ID PC network members also. When ontosystem variables relating to other members of the Intellectual Disability Palliative Care Ecosystem are included (as outlined in Table 8), the potential for cumulative complexity is clear. For example, cumulative complexity may develop in a situation when a person with intellectual disability and life-limiting condition experiences pain but is unable to communicate verbally and instead signals distress by displaying challenging behaviour which may in turn challenge the ability of non-ID staff to engage with the person and effectively meet their needs. Working relationships between ID and non-ID staff may become strained by historic and current failure to meet the person with intellectual disability's needs, which may further impact negatively on care.

Table 8 Ontosystem variables relating to the Intellectual Disability Palliative Care Ecosystem

Ontosystem variables		**Description**
Family	Relationship	The relationships (e.g., mother, cousin) between people with an intellectual disability and families influenced the family member's emotional response and impacted complexity.
	Attachment & contact	Strength of relationship and regularity of contact varied significantly between family members and between people with an intellectual disability. The development of a life-limiting condition can affect family deeply and intensify emotional responses.
	Caregiving responsibilities	Caregiving responsibilities often intensified in the setting of serious illness which could result in a need for additional supports or carer fatigue. In situations where the needs of between the person with an intellectual disability exceeded the family member's ability to provide care, complex feelings of guilt and distress could arise. Additionally, situations arose where family members had multiple caregiving responsibilities, and the illness of the person with an intellectual disability heightened the complexity of the family member's need.
	Prior experience of loss	Previous multiple or traumatic losses heighten complexity of grief.
	Coping capacity & resilience	Coping capacity and resilience help to mitigate against compassion fatigue, burnout, and adverse mental health effects of providing care, and reactions to grief and loss.
	Self-efficacy	High perceived self-efficacy in palliative care provision mitigated against complexity.
	Attitude towards healthcare professionals (HCP)	Openness towards collaborative working and a trusting basis to the family- HCP relationship alleviated complexity while over-protectiveness or a reluctance to engage in shared-decision making heightened complexity.
	'Second family'	Openness to considering family and people with an intellectual disability who were receiving ID services as 'second family' mitigated against complexity and facilitated inclusion of ID staff and peers in the illness journey and mourning rituals such as funerals.
ID staff	Relationship	ID staff described their relationships with people with an intellectual disability in a variety of ways that included consideration of people with an intellectual disability as a 'second family'. Relationships were often long and close, increasing the complexity of the staff member's emotional reaction.
	Prior experience of loss	Previous multiple or traumatic losses heighten complexity of the grief experience.

	Coping capacity & resilience	Coping capacity and resilience help to mitigate against compassion fatigue, burnout, and adverse mental health effects of providing care, and reactions to grief and loss.
	Self-efficacy	High perceived self-efficacy in palliative care provision mitigated against complexity.
Peers	Intellectual impairment	Severity of cognitive impairment impacted on understanding and response to the illness of a peer. Staff felt that they lacked skills to assess and support peers.
	Communication impairment	Severity of communication impairment impacted on the ability of peers to ask questions, communicate emotions, or articulate needs. It impacted on the ability of carers to provide information, identify needs and response to care or provide support.
	Care needs	Peers frequently had care needs of their own that could sometimes intensify in reaction to the illness of a peer. The ability of staff to provide care that to meet both the needs of the individual with serious illness and peers could be impacted by increased demands in the setting of inadequate resources.
	Challenging behaviour	Prior history of challenging behaviour could lead to a tendency for staff to exclude individuals from participating in the illness journey of their peer. The ability of staff to anticipate or respond to challenging behaviour in the setting of increased caring responsibilities could be compromised.
	Living arrangements	The living arrangements of people with an intellectual disability living in residential care are often not future-proofed for ageing in place or managing situations where residents become seriously unwell. For example, peers may be impacted by the need for additional equipment or staff in the house, or for the need to change bedrooms or routines.
	Relationship	The relationship between peers with intellectual disability varies, nonetheless peers are affected by the illness and death of a person that is known to them and experience feelings of loss and grief. In situations where relationships are long or close, the impact can be profound.
	Prior experience of loss	People with an intellectual disability are at higher risk of complicated grief that the general population. In addition, previous multiple or traumatic losses heighten complexity of the grief experience.

The mesosystem: the interactions between the person, their family and health professionals

The mesosystem typically encompassed interactions between the person with an intellectual disability, family, ID staff, peer group, specialist palliative care staff, and extended healthcare professionals. Although the settings of care most commonly involved home, they could also include acute hospitals, hospices, different types of residential care settings, and day activation settings. There was notable variation in the number of links evident between the various microsystems- for example, interactions between ID staff and family, ID staff and SPC staff and SPC staff and family were commonly observed, however interactions between SPC staff and peers appeared infrequent. While some microsystems explicitly and implicitly shared or encouraged similar behaviours and values, other microsystems functioned through conflicting or contrary practices and values. In situations where there was coherence in the mesosystem, this was associated with reduced complexity, whereas the converse was true in mesosystems with a high level of fragmentation or incoherence.

The following mesosystem themes were observed: ***quality of family-staff relationships;*** [33, 36, 78, 83, 85, 88, 96, 102, 106, 110-112, 114, 126] ***ID multidisciplinary team (MDT) composition and working;*** [36, 37, 78, 87, 89, 91, 96, 101, 102, 106, 110, 111, 118, 119, 121, 128] ***broader system MDT working;*** . [36, 37, 49, 82, 89-91, 93, 95, 96, 98, 100, 103, 105, 110, 117, 121, 128] ***availability and exchange of information;*** . [36, 83, 87, 89, 91, 92, 103, 105-107, 111, 119, 128] ***decision-making;*** [37, 83, 88, 96, 111, 112, 114, 116, 118, 126, 128] ***training and experience;*** [33, 36, 78, 98, 102, 106, 107, 109, 110, 127] ***and place and impact on peers.*** [49, 83, 88, 93, 117-119]

Quality of family-staff relationships

Complexity was associated with dissonance in family-staff relationships. A variety of factors could ameliorate or exacerbate dissonance in relationships and resultant complexity. These included individual openness to developing relationships, working collaboratively, and sharing decision-making. The personal attributes of staff were important and family members were more likely to build trusting relationships with staff whom they viewed as being kind, honest and sincere. Equally, the personal attributes of family members were important and complexity was heightened in situations where families were experiencing complex grief reactions, where they were perceived as being ‘over-protective’, or where they had difficulty processing and using information relating to the care of the person with an intellectual disability. A particularly influential factor was whether family members had a strong and sustained trusting relationship with the person with an intellectual disability or whether the diagnosis of the life-limiting condition had prompted re-connection. In the latter situation, complexity was heightened if staff felt ‘pushed out’ by the re-establishment of family connections. Communication style was key to the development and maintenance of relationships; family members valued sensitive but clear and timely communication with staff who recognised and appreciated the role and contribution of family members to the care of the person with an intellectual disability. A shared value system where each person was committed to the provision of person-centred care and the best interests of the person with an intellectual disability helped families and staff navigate decision-making and care planning. However, instances where there were different opinions about communicating with the person with an intellectual disability, involving them in decisions or disagreeing about what was in the person best interests could lead to dissonance and increased complexity. Instances where there was ambiguity relating to respective roles in decision-making also added to the burden of decision-making and increased complexity.

ID multidisciplinary team (MDT) composition and working

The composition and ways of working of the ID multidisciplinary team was a second mesosystem theme. Teams that were fully staffed with a comprehensive range of disciplines were better placed to respond to the palliative care needs of people with an intellectual disability and to address complexity. The knowledge base and experience of the team were also important factors, and the complexity was understandably heightened in situations where teams lacked familiarity and proficiency in managing palliative care needs and end-of-life care. Complexity was reduced when ID teams communicated effectively and had established ways of care planning and making decisions collaboratively. This was because team functioning improved in these situations. Shared values were of fundamental importance to team function. Although teams operated in environments where all shared a belief in person-centred care, promotion of autonomy and enablement, differences were at times evident in the operationalisation of these values or in individual beliefs and experiences informing decision-making (e.g., misperceptions regarding analgesia, personal history of bereavement).

Broader system MDT working

A third mesosystem theme related to the broader multidisciplinary team that comprised ID staff and external healthcare professionals such as specialist palliative care. Team openness to engagement with external teams, such as hospital and specialist palliative care teams demonstrated variability. In general, teams were more open to seeking help from specialist palliative care as prior experience of working with hospital teams had often been negative. While specialist palliative care services were in turn generally open to providing care, on occasion hidden prejudices or misperceptions could act as a barrier to service provision. In common with factors influencing ID multidisciplinary team function, openness to collaboration, effective communication and decision-making, shared beliefs and values all reduced complexity, whereas dissonance heightened complexity. Of interest, reflective practice was seen as a valuable way to improve care and collaboration between different organisations.

Availability and exchange of information

Information availability and exchange was a fourth mesosystem theme of importance. Information in all forms- about the person with an intellectual disability, the illness, expected prognosis and care plan, the person's family, and how to navigate the healthcare system and provide care was regarded as essential for both family members and staff. However, all too often there were gaps and uncertainties in information provided which increased stress and distress.

The hospital setting was regarded as one where information availability and exchange was particularly problematic and complexity of care was increased as a result. Conversely, the GP was regarded as an individual who could have a positive impact on information provision. Information availability was not the sole arbiter of complexity, information symmetry was also important as complexity was increased in situations where either family or staff lacked salient information or was less able to use it effectively in decision-making.

Decision-making

Decision-making emerged as further mesosystem theme. Both the nature and the process of decision-making impacted on complexity. Family and ID staff spoke of the magnitude and responsibility associated with making end-of-life decisions. Decisions focused on nutrition, hydration, pain control and withdrawing or withholding interventions were ones that often impacted on individuals emotionally as well as morally. As such, when the need to make such decisions arose, complexity was heightened. The process of decision-making could further influence complexity. Sometimes staff and family held different opinions about whether (or to what degree) the person with an intellectual disability should be involved in the decision-making process. At other times, staff and family agreed that the person with an intellectual disability lacked capacity to be involved in the decision-making process but disagreed between themselves as to who was best placed in the decision-making process. When decision-making was a shared process between staff and family, then sometimes roles and responsibilities could be unclear and communication sub-optimal. Complexity could also arise in situations where the person with an intellectual disability was involved in decision-making. This most commonly occurred in situations where there was conflict between respecting the autonomy of a person with an intellectual disability and acting according to what was perceived to be in their best interests. Staff spoke of the difficulty of allowing people with an intellectual disability to make ‘unwise’ decisions.

Training and experience

The theme of ‘training and experience’ emerged as one of the most commonly cited factors contributing to the challenge of providing palliative care.[33, 36, 78, 98, 102, 106, 107, 109, 110, 127] ID staff frequently felt inadequately prepared to provide palliative care while palliative care staff felt that they lacked skills in managing and engaging with people with an intellectual disability. The inequitable access to specialist palliative care services that people with an intellectual disability experience further compounded the issue, as opportunities for collaboration, relationship building and mutual learning were relatively infrequent. Family members also pointed to occasions where they were inadequately prepared or supported in their caring role. [95, 128]

A final mesosystem theme observed was that of ‘place of care and impact on peers’. When the person with an intellectual disability and life-limiting illness lived in shared residential care, the impact of illness was noted to extend to peers with an intellectual disability. Although the nature of the relationship between residents was noted to vary widely, it was generally accepted that peers themselves experienced an emotional reaction to the illness of their fellow resident. There was a need to consider issues of information provision and support for the peers, as well as continuing to support the person with the life-limiting condition. The demands of providing care for the unwell individual often required so much time and effort that staff were concerned that they were not able to meet the needs of other residents. Moreover, the routine and living arrangements of residents could be disrupted resulting in anxiety and distress. Such factors were all felt to add considerably to complexity of care. Such complexity appeared to be often hidden to specialist palliative care staff however, and it was notable that peers were not regarded as being part of the ‘unit of care’ that specialist palliative care teams provide services to. A number of factors were observed to alleviate complexity however- the personal characteristics of peers could vary, with some experiencing less distress than others. ID staff also commented that proactive preparation, support and appropriate inclusion of residents in the illness journey was of value in mitigating distress. Indeed, fellow residents could have a valuable role to play in maintaining friendships and acting as supports to the person with serious illness.

The exosystem: service- and system level factors

Exosystem influences are those that are external to the microsystem but that nevertheless impact on the experience of palliative care need. Three main exosystem themes were apparent: ***resourcing;*** [33, 36, 37, 83, 90, 93, 96, 98, 101, 103-107, 109-112, 115, 117, 119] ***integrated care;*** [36, 37, 82, 90, 91, 94-96, 98, 102, 103, 105, 117, 121, 128] ***systems of information provision and decision-making.*** [36, 83, 87, 89, 91, 92, 105, 106, 119, 128]

Resourcing

The type and availability of resources available to staff and families to support the care of the person with intellectual disability and life-limiting illness varied considerably. The meaning of resources encompassed both physical resources (equipment, space, living environment), staff (numbers, breadth of team), emotional supports, training and education necessary to provide care, and sufficient time to provide care. Generally, resourcing was felt to be inadequate, and this contributed to perceptions of complexity. Staffing levels were often not increased in line with increased demands of providing care, and the range of the MDT was limited with social work, psychology and chaplaincy support often neglected elements of care provision. The emotional demands on staff who were providing care appeared to be often hidden and supports that were noted to be of value (time for team meetings, peer support, debriefing, remembrance events) were inconsistently available. The importance of ensuring that supports continued into the period after death to support bereavement was noted but variably implemented.

Integrated care

A second theme was that of integrated care. Where there were established relationships between services and effective collaboration, care was felt to be qualitatively different. It was felt to be more consistently person-centred, coordinated, and effective. Teams experienced fewer barriers to providing care and were enabled to work to their maximum ability. As a result, complexity was reduced. All too often, however, care was provided in silos with little evidence of joined up thinking or approaches.

Systems of information provision and decision-making

Although information is an important component of integrated care, systems of information provision emerged as an independent theme because of the emphasis placed on the topic in data and because of the breadth of the concept. High value was placed on both the availability of information and the way that decisions were made based on information. Complexity was increased when information regarding care or service availability was unavailable, incomplete, or ambiguous. The timing of information provision was felt to be important, and services were felt to be on the back foot when information was provided late in the disease trajectory. Although adequate information improved decision-making, it did not guarantee high quality decision-making processes and findings pointed to the importance of ensuring that transparent, collaborative systems of decision-making were in place. Effective multidisciplinary team meetings and family meetings were regarded as key to this. Once a care plan had been formulated, the importance of ensuring that this was readily available to all team members was also emphasised. Wherever possible, advance care planning was felt to lessen complexity as it meant that decisions were made in a planned and proactive manner. Policies, guidelines, and other systems of decision-support were also valued.

The macrosystem: population and society

Three macrosystem themes were identified: ***person-centred care,*** [89, 90, 96, 111, 112, 115, 116, 119] ***legislation,*** [99, 101, 105, 106, 126] ***and financing.*** [36, 79, 89, 93, 96, 103, 109, 110, 117, 119]

Person-centred care was a macrosystem theme. While all healthcare organisations should strive to provide person-centred care, it was often felt that this was realised to a greater degree and in a qualitatively different way in ID and SPC settings compared to hospital settings. In person-centred care, healthcare professionals work collaboratively with people who use services. Person-centred care supports people to develop the knowledge, skills, and confidence they need to make informed decisions. It is coordinated and tailored to the needs of the individual. Crucially, it ensures that people are always treated with dignity, compassion, and respect. [133] Settings varied in the degree to which this vision was realised for people with an intellectual disability- particularly in the degree to which the autonomy of people with an intellectual disability was respected and promoted. A variety of reasons for this variability was evident- in some cases, people with an intellectual disability were felt to be stigmatised or marginalised, in others there was a lack of education or understanding regarding the unique needs of people with an intellectual disability, or carers lacked time, resources or skills to put person-centred care for people with an intellectual disability into practice. Complexity was lessened when organisations or peoples within settings practiced within similar cultures of person-centred care as roles, activities and relationships were more predictable and congruent. Engagement with people whose traditions, beliefs and experiences are different from one's own was associated with complexity.

The legislative environment was a related macrosystem theme that also impacted on complexity. The complicated and sometimes ambiguous environment of capacity legislation was felt to pose significant challenges to practice. Although legislation is enacted at a national level, and so is applicable to all settings within a country, it was evident that some organisations were better placed to navigate the complexities associated with formal decision-making processes. Experience, training, and adequate resourcing were all factors that were observed to alleviate complexity in this area.

The final theme of financing of care related to the funding provided for the provision of health and social care. The type and availability of funding provided to services varied widely across settings with a direct impact on the resources available to the person with an intellectual disability and their family. Funding constraints limited the quantum and type of support that organisations were able to provide. Inadequate resourcing led to further complexity in the management of those individuals who required intensive input from a broad range of disciplines.

The chronosystem

The chronosystem refers to changes in a patient's needs, circumstances and environment over time. [61] Two chronosystem themes were identified: ***disease trajectory*** . [78, 93, 109, 111, 116, 117, 120, 127, 128] ***and organisational development.*** [37, 82, 90, 91, 103, 105, 110, 117, 121, 128]

The trajectory of a person's illness was noted to impact on complexity in a variety of ways First, an uncertain trajectory was one that increased complexity as it made it more difficult for care to be planned and provided effectively. Sometimes the underlying characteristics or nature of the disease process meant that the trajectory was uncertain, but at other times the trajectory was perceived to be uncertain because carers lacked information or understanding of the disease process and so were unable to interpret or recognise signs of decline. Second, a short trajectory (e.g., due to delayed diagnosis or rapid disease trajectory) was one that increased complexity as it limited opportunities for preparation and planning and meant that staff more often provided care in a reactive rather than proactive manner. Conversely, a prolonged or very lengthy disease trajectory could also at times be associated with complexity when carer fatigue occurred, or resource constraints developed. Third, times of increased need were noted over the course of the disease trajectory (e.g., at time of diagnosis, deterioration, or end-of-life) and those times were often experienced as times of increased complexity.

The theme of organisational development relates to the changes that occurred over time as modern legislation relating to capacity was implemented and demographic changes in service user populations became apparent. In response to these events, greater emphasis was placed on recognising and supporting the autonomy of people with an intellectual disability, embedding best practice in decision-making and in educating and training staff.

2.8 Discussion

The above analysis has synthesised the literature to present a typology of palliative care need and used an eco-biological framework to describe and interpret micro-, meso-, exo-, macro- and chronosystemic influences on complexity of palliative care need. Figure 2 presents a conceptual model of the intellectual disability palliative care ecosystem based on the integrative literature review analysis and findings.

Figure 2 Intellectual disability palliative care ecosystem v1 [7]

Microsystem themes:
- 'Knowing'
- Time
- Normality

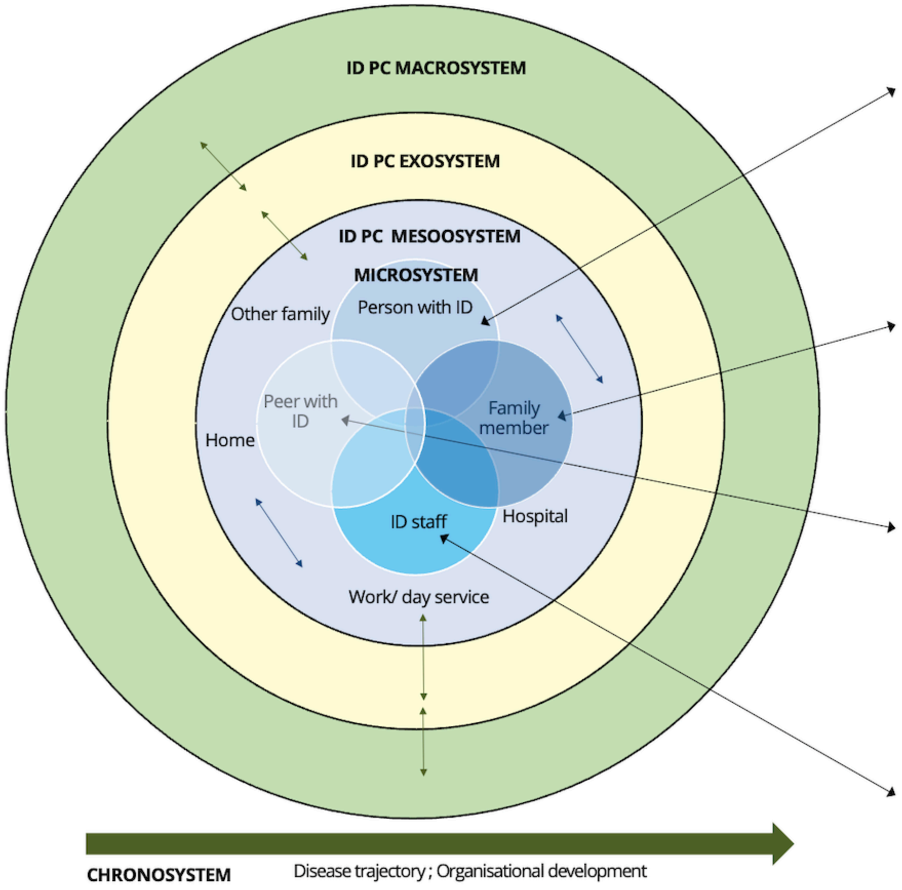
Mesosystem themes:
- Family-staff relationships
- ID MDT composition & working
- Broader system MDT working
- Availability & exchange of information
- Decision-making
- Training & experience
- Place of care & impact on peers

Exosystem themes:
- Resourcing
- Integrated care
- Systems of information provision & decision-making

Macrosystem themes:
- Person-centered culture
- Legislative environment
- Financing of care

Chronosystem themes:
- Disease trajectory
- Organisational development

PC needs of the person with ID (physical , psychosocial, emotional, spiritual, communication, decision-making, time & continuity of care, disability-related); PC needs of family; PC needs of ID staff; PC needs of peers



Person with ID ontosystem variables:
- Intellectual impairment
- Communication impairment
- Physical disability
- Functional decline
- Chronic illness
- Mental health
- Challenging behaviour
- Experience of a life of loss

Family member ontosystem variables:
- Relationship
- Attachment & contact
- Caregiving responsibilities
- Prior experience of loss and death
- Coping capacity & resilience
- Self-efficacy
- Attitude towards HCP

Peer ontosystem variables:
- Intellectual impairment
- Communication impairment
- Care needs
- Challenging behaviour
- Living arrangements
- Relationship
- Prior experience of loss

ID staff member ontosystem variables:
- Relationship
- Prior experience of loss and death
- Coping capacity & resilience
- Self-efficacy

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[7] PC= palliative care; ID= intellectual disability; HCP= healthcare professional

The model captures needs and ontosystem variables relating to not only the person with intellectual disability and life-limiting illness, but also their peers, family, and ID staff. In this way, the model considers the four categories of individuals within the 'unit of care' and the ecosystem. This is a novel departure from processes of palliative care provision typically represented in the literature to date which typically focus on the person with an intellectual disability and their family only. The model highlights how peers with intellectual disability and staff also experience needs and how complexity can be affected by interactions between variables relating to different actors in the ecosystem.

2.8.1 Meeting the needs of people with intellectual disability and life-limiting illness

Previous reviews of the palliative care needs of people with an intellectual disability [2, 134] and the European Association for Palliative Care Consensus Norms [105] emphasise that many of the palliative care needs of people with an intellectual disability are no different from those of the general population. Focus is placed on recommending that palliative care services know how to adjust their services in order to make them accessible to people with an intellectual disability. While the broad thrust of this statement remains true, it is suggested that the findings of this integrative review add to the field by providing a more detailed and nuanced view of the situation faced by those providing generalist and specialist palliative care services to people with an intellectual disability.

In viewing the needs of people with an intellectual disability through the lens of the ID PC framework, it is apparent that experience and complexity of need are shaped by a variety of factors operating at different levels and interacting in complex ways. Focusing on interventions that aim to reduce barriers to palliative care will not address need comprehensively. Instead, a holistic approach will be required that incorporates interventions aimed at multiple levels, including at levels falling outside the influence of specialist palliative care services. Moreover, the assertion that many of the palliative care needs of people with an intellectual disability are 'no different' to the general population fails to adequately consider the factors specific to impairment (or the social consequences of impairment) that interact and exert influence on experience of need and complexity. Without full appreciation of relevant factors, interventions to alleviate complexity and address need will fail to have maximum effect.

The findings of the integrative review highlight that while the palliative care needs of people with an intellectual disability may be classed within the familiar domains of physical, emotional, psychosocial, and spiritual need, particular need arises also within communication, decision-making and continuity of care domains. The needs are sufficient magnitude and importance to merit consideration and attention on a regular basis when providing palliative care to people with an intellectual disability. In addition, while categorisation of need may fit to a large degree within conventional domains, the interactions that people with an intellectual disability and palliative care needs have with others depend both on the personal characteristics of all involved and also on the contexts in which interactions occur.

For example, people with an intellectual disability and communication impairments will engage differently with specialist palliative care staff compared to those without; people with an intellectual disability who have experience of traumatic separations will react differently to changes in staff relationships to those who live within a stable family structure; a family who shares similar values and beliefs to ID staff about nutrition at the end-of-life will find it easier to reach agreement on a feeding care plan; the way in which a residential care setting is organised clearly impacts on the ways in which care can be delivered in comparison to a hospice setting. In addition, what happens in one context also influences what goes on in other contexts- families who have had negative experiences dealing with healthcare professionals will engage quite differently with palliative care teams compared to those that have had good experiences. The ID PC ecosystem illustrates how having a fuller conceptual understanding of the ecosystems that people with an intellectual disability and life-limiting conditions inhabit is core to tailoring services to meet needs.

The ID PC ecosystem helps direct attention to factors that are more readily modifiable than others when aiming to improve service provision for people with an intellectual disability. For example, the value of maintaining psychosocial networks was identified as an important element of maintaining normalcy and also of providing emotional support. This is something that is feasible to achieve in the short-term with care and consideration, whereas future-proofing shared living spaces to maintain normalcy is something that requires greater planning and resource input. It is important to ensure that the issue of suitable living space is addressed, nonetheless, as the inter-related nature of the ecosystem demonstrates that disrupted living spaces can lead to peer distress which in turn can impact on staff workload and ability to provide care to the person with life-limiting illness. A cycle of escalation thus ensues.

The ID PC ecosystem also helps direct attention to factors where there has been a relative lack of progress detailed in research or practice solutions to areas of challenge. For example, collaboration between ID and SPC services is regularly proposed as an optimal model of service provision and yet the review findings indicate that even when services collaborate, areas of suboptimal practice remain such as gatekeeping or over-reliance on proxy reporting. In contrast, research on advance care planning has led to better understanding of how to assess readiness to engage in conversations and how to involve people with an intellectual disability in advance care planning. [135, 136]

2.8.2 Meeting the palliative care needs of staff working in intellectual disability services

The review demonstrates the importance of considering the needs of ID staff and of including them within the unit of care provided when this is needed. ID staff are frequently personally affected when providing palliative care to people with an intellectual disability. They feel grief and loss as part of the illness journey and can also experience a burden of caregiving that they are ill-equipped and prepared for. Support is merited on this basis alone, but also on the basis that they are fundamental to the care of the person with intellectual disability and life-limiting illness and their peers. The inter-relationship between the personal experiences and characteristics of staff and their ability to provide emotional and psychosocial support, as well as communicate about illness, death and dying is apparent. Education and training are critical to competence, but emotional wellbeing is critical to confidence.

The role of ID staff in the provision of palliative care is somewhat unique, as observed by Brown, 'at one end of the spectrum they move into a space which families and close relatives might otherwise occupy, while at the other end they have to take on nursing tasks which are outside their usual professional role.' [80] The ambiguity and complexity of that role may help explain why there was little evidence of a comprehensive response to their needs being developed or implemented in the evidence reviewed. However, the synthesis of evidence did give clear direction to the factors that alleviated complexity, and which should be considered in a whole systems response to staff need. This includes the following: training and education to build self-efficacy and competency; additional supports and resources to alleviate the burden of caregiving and more effectively meet the needs of the person with intellectual disability; pro-active planning where possible to allow for preparation and adaptation to need; acknowledgement of the meaning and significance of the staff-client relationship and facilitation of effective team-working, peer support and reflective practice; implementation of systems of decision-support and best practice in decision-making and integrated ways of working with the specialist palliative care and the wider health system.

2.8.3 Meeting the needs of peers with an intellectual disability

The review also pointed to the importance of including peers with an intellectual disability within palliative care service provision- another overlooked area, particularly from the perspective of specialist palliative care providers. Findings pointed both to the contribution that the peers could make to the emotional and psychosocial wellbeing of the person with serious illness, but also to the range of impacts that could be experienced by poorly supported or ill-prepared peers. Residents may experience disruption to their normal routine, staff may be diverted towards caring for the individual with terminal illness and residents may experience emotional reactions to change, grief and loss. The impact of such experiences may continue to exert effect when the peers themselves come to face their own illnesses and death. Evidence of pro-active and planned interventions to pre-empt or respond in a timely way to peer need was lacking despite the heightened vulnerability of peers to complicated grief.

The evidence synthesis points to factors that can affect the complexity of need experienced by peers and suggests where interventions may be focused to ameliorate or respond to need. For example, it portrays the value of including people with an intellectual disability in the normal cycle of life and supporting their emotional and/ or cognitive understanding of illness and death. It points to the value of more comprehensive planning for ageing in place so that planning includes consideration of the impact of any eventual illness on the whole household. This may include helping families understand the important place that peers play in the social network of people with an intellectual disability and helping individuals navigate the complexity of having 'two families.' In the event of a peer becoming unwell, adequate supports and resources should be put in place to meet the needs of peers as well as the sick person. Where possible peers should have opportunity to say goodbye and bereavement supports should be provided.

2.8.4 Meeting the needs of family members

In comparison to the preceding groups, the palliative care needs of family members are more clearly acknowledged and met in traditional models of palliative care provision. A body of literature exists that has moved beyond descriptive to interventional methods considering how to meet family member needs. [137-139] Focus has been given as how to best identify those with complex needs within the overall population, and how to identify those at particular risk of adverse outcomes. [138] Within this general body of work, family members of those with chronic illness or disability are recognised. However, there has been a relative lack of focus on the specific palliative care needs of family members of people with an intellectual disability in comparison to other populations, such as those with cancer. [30, 140-142] This is important as there is awareness that different terminal illness diseases and experiences translate into different family caregiver experiences, leading to both similarity and difference in caregiver needs and effective interventions.

Given that the palliative care needs of family caregivers are at least recognised in the wider literature, it was an unexpected finding that the needs of family caregivers were not a more substantial focus within the papers included in this review. It is hypothesised that this is reflective of the fact that many articles focused on care provided in institutional or residential care settings where there was an increased likelihood that people with an intellectual disability had been separated from their families. It points to an area whether further study is merited. Nonetheless, a range of family needs were identified by the review, together with identification of factors that impacted on complexity. The findings point to the merits of ID services establishing communication and relationships with family members in a proactive and planned way from the earliest point of engagement with services (in advance of the development of any life-limiting condition). In this way, communication is regarded as 'normal' part of service provision and relationships are formed in circumstances outside of palliative care settings. Services should also respond to family information and decision-support needs more specifically relating to palliative and end-of-life care, providing education and emotional support, and developing a shared understanding of roles and responsibilities in care planning. A range of factors were identified that could heighten complexity in staff-family engagement ranging from complex family dynamics, to dissonance in staff-family relationships, to navigating with ethical dilemmas. In such situations, the input of skilled and experienced staff (such as social workers or specialist palliative care team members) and the establishment of a common commitment and focus on the needs of the person with an intellectual disability was perceived to be of importance.

2.8.5 Limitations:

This review has a number of limitations. The search included seven databases but limited articles to those published in English and did not include the grey literature. This may have limited scope and introduced publication bias; however, no date or geographical restrictions were applied, and hand-searching of reference lists was conducted. The literature review process was conducted by one author (KR) and this presents a source of bias. Full details of the audit trail are provided to ensure transparency of decision-making. As discussed, Pask's adapted model was used as theoretical frame for analysis and the variables presented are descriptive and may not fully represent factors that might influence complexity. All aspects of bioecological theory are not investigated within this model.

2.9 Conclusion:

This integrative literature review aimed to synthesise the current evidence regarding the palliative care needs of people with an intellectual disability and those close to them, and to synthesise key elements associated with definition of complexity in the provision of palliative care to people with an intellectual disability and those close to them. It has resulted in the development of a taxonomy of palliative care needs and a conceptual model of complexity that contributes to the original literature by organising existing findings into a cohesive and meaningful picture that goes beyond simple groups of associations. In contrast to the role that previous literature reviews have played in identifying, evaluating, and summarising the findings of all relevant individual studies, this integrative review has generated a taxonomy and model illustrating the relationships between variables that influence complexity, and pointing to where greater support and intervention would be of value. In this way, it also offers value in pointing to future directions for further research.

Chapter 3. Methods

3.1 Introduction

This chapter provides a narrative of the methodology employed in the IDS-TILDA End-of-Life Study. The methodology begins with a description of the mixed-methods design and study aim. The historical foundations and philosophical underpinnings of mixed-methodology research are presented along with the rationale for using a convergent parallel design. A procedural diagram illustrates the study's sequence. Next, the sampling strategy for the IDS-TILDA End-of-Life Study is discussed. The quantitative and qualitative strands of the End-of-Life Study are presented with description of data collection procedures, instrumentation and method of analysis for each strand and their integration. This chapter concludes with ethical considerations. Analytic findings are presented in Chapter 4.

3.2 Aim and objectives:

The aim of this convergent parallel mixed methods study is to understand the end-of-life care experiences and service utilisation of people with intellectual disability in Ireland from the perspective of bereaved caregivers by combining the quantitative and qualitative data collected. The study's objectives are to address key gaps in the knowledge base regarding palliative care provided to people with an intellectual disability in Ireland by investigating: 1) the trajectory of illness and cause of death of study participants 2) place of care and place of death 3) services utilised in the last three months of life 4) stakeholder experience of receiving and providing palliative care.

The application of mixed methods in this study is informed by the definition of Creswell and Plano Clark (2017, p 4-5)[143] that combines a methods, research design and philosophy orientation, and which highlights the key components that go into designing and conducting a mixed methods study. That is, in mixed methods, the researcher:

- 'Collects and analyses both qualitative and quantitative data rigorously in response to research questions and hypotheses.
- Integrates (or mixes or combines) the two forms of data and their results.
- Organises these procedures into specific research designs that provide the logic and procedures for conducting the study and
- Frames these procedures within theory and philosophy.'

In this study, quantitative IDS TILDA and survey data provides a description of variables such as illness trajectory, services received in the last three months of life, cause and place of death and stakeholder opinion regarding the quality of care received. Qualitative interview data provides nuance, context and understanding to the relationships between micro-, meso- and macro-aspects of healthcare provision and how those relationships ultimately inform experience.

3.3 Historical, philosophical, and theoretical foundations of mixed methods research

Historical foundations

Although the combination of quantitative and qualitative data had been previously suggested, the evolution of mixed methods research is generally considered to have gained prominence in the 1980s. By this time, qualitative methods had gained acceptance and there was growing understanding of the fact that the complex problems required increasingly sophisticated methods of analysis. Creswell and Plano Clark [143] describe five historical stages of development as follows:

1. The formative period (1950s-1980s) where interest in use of more than one method grows [144-146]
2. The paradigm debate period (1970s- mid 1990s) where debate takes place about whether quantitative and qualitative data could be combined or whether differing philosophical assumptions makes this impossible. [147, 148]
3. The early procedural development period (1980s- 1990s) where focus shifted to more detailed consideration of design and purpose, methods of data collection and analysis. [147, 149]
4. Expanded procedural development period (ongoing since 2000s) where formalisation of the field occurs [150-152]
5. Reflection and refinement period (ongoing since 2003) where controversies and issues of concern lead to reflection and refinement of methods and further advancement of the field. [153-155]

Philosophical foundations

Creswell and Plano Clark [156] suggest that four philosophical paradigms are commonly used in mixed methods research- postpositivist, constructivist, transformative and pragmatist. It is important that researchers make clear the paradigm from which they are operating to identify assumptions inherent to each worldview. In keeping with the work of Tashakorri and Teddlie, [148] pragmatism is the paradigm that has informed this study. In pragmatism, primary importance is placed on the research question that is being asked and the forced choice between the nature of truth and reality can be avoided. Instead, a practical and applied research philosophy guides methodological choices, both objective and subjective knowledge are valued, and methods are oriented towards 'what works.' According to Feilzer (2010, p.14), [157] pragmatism circumvents the quantitative/qualitative divide and ends the paradigm war by suggesting that the most important question is whether the research has helped to find out what the researcher wants to know.

The emphasis on interrogating the value and meaning of research data through examination of its practical consequences [158] is of value in healthcare organisations where practice is closely intertwined with the ways in which knowledge is produced. Pragmatism enables a focus on the exploration and understanding of the connections between knowledge and action in context. Biesta has observed that 'knowing' in this sense, has the potential to transform practice. [159] Pragmatism also offers opportunity to utilise an abduction-intersubjectivity-transferability approach [160] where reasoning moves back and forth between induction/deduction and subjectivity/objectivity and where uncertainty and instability are accommodated alongside scientific rigor and theory. Sandelowski argues that knowledge obtained by such practical approaches is not pedestrian but particular, and that it satisfies needs to improve the daily lives of individuals. [161]

These are important consideration given the overall goal of IDS-TILDA is to understand the determinants of health and well-being for people ageing with an intellectual disability and to use this data drive evidence informed policy making and to improve the lives of people with an intellectual disability. The emphasis that pragmatism places on research emanating from a desire to produce useful and actionable information guides the anchoring of research questions in respondent experiences and hence, ensures the research is of practical relevance. Given the complex nature of end-of-life care and the desire to obtain both an in-depth understanding of experience and generalisable data, the paradigm of pragmatism has enabled a pluralistic stance to be adopted where there is collection of different kinds of data in the same phase, which are then merged.

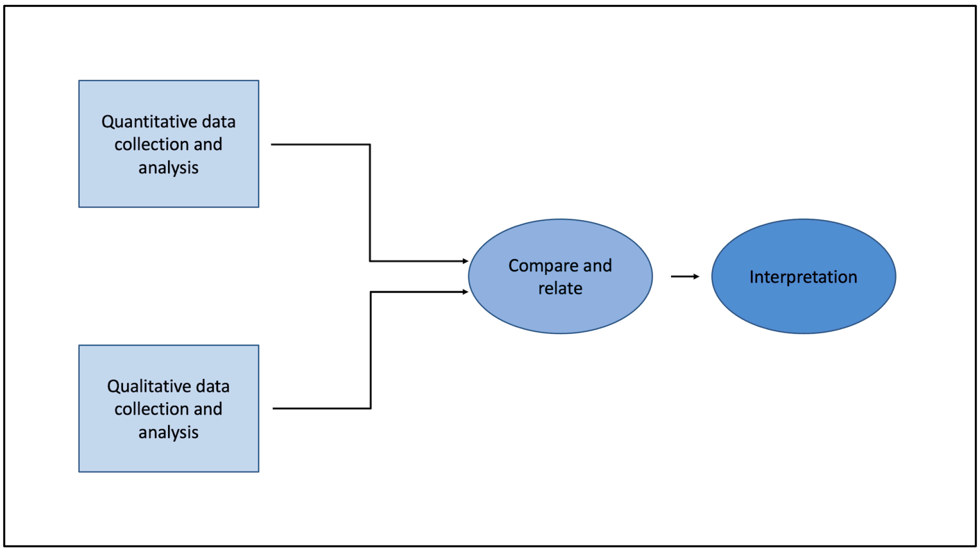
Theoretical foundations

Eisenhart defined a theoretical framework as 'a structure that guides research by relying on a formal theory...constructed by using an established, coherent explanation of certain phenomena and relationships' (1991, p. 205). [162] As such, theoretical frameworks may be understood as 'blueprints' for inquiry. In this thesis, Pask's framework for complexity in palliative care [60] has been used to guide consideration of the literature review and data analysis. Complexity is of central importance to palliative care provision because is used to describe the nature of patients' situations and the extent of resulting needs and care demands. [60] Understanding and ranking levels of complexity helps to distinguish between generalist and specialist palliative care needs and service responses.

3.4 Design:

A convergent parallel mixed methods study design is used. This approach involves the simultaneous development of qualitative and quantitative datasets followed by the combination and comparisons of these multiple data sources. The approach is also referred to as the concurrent triangulation design (single-phase) because the data is collected and analysed individually but at the same time, see Figure 3. The intent of convergent design is 'to obtain different but complementary data on the same topic' to gain optimal understanding of the research problem. [163] The data from each database is typically prioritised equally which is the case in this study. In the interpretation phase, side by side analysis examines the data looking for convergence, divergence, contradictions, or relationships between the two sources of data.

Figure 3 Convergent parallel design



3.5 Ethics

Ethical approval

The IDS-TILDA and End-of-Life Study received ethics approval from the Faculty of Health Sciences Ethics Committee at Trinity College Dublin and all the participating services providers (n = 138). All respondents provided informed consent. Data has been anonymised and pseudonyms (including for place names) are used in the reporting of the data.

Ethical considerations

The challenges of conducting palliative care research are well recognised and include both methodological and ethical considerations.[164, 165] Research in palliative care often is considered to be sensitive because researchers engage with vulnerable populations. Careful consideration must be given to the consideration and mitigation of risk when engaging in research with vulnerable populations. Given the sensitive topic that is the focus of this study and the role of bereaved caregivers as respondents, a number of particular areas of risk were identified and addressed in this study.

Management of risk during initial contact

The recruitment and initial contact with bereaved caregivers were recognised as points of potentially elevated risk. It was essential that contact was managed sensitively and appropriately. Given that this study forms part of the larger IDS-TILDA longitudinal study, the project benefitted from the relationships that had already been established between the IDS-TILDA research team and participating service providers. In order to minimise distress and to adhere to the principle of non-maleficence, contact was first made with service managers of IDS-TILDA decedents. The service managers were asked to identify the person who was the 'key caregiver' for the decedent and who was best placed to provide information. The service managers were also asked at this point whether there was any reason not to contact the individual that should be considered. Providing that no concerns were identified, contact was then made with the bereaved caregiver by letter. Bereaved caregivers have identified that a letter is the least intrusive form of initial contact as it allows the person time to consider the request before direct contact is made by research teams.[166]

Careful consideration was also given to the time period advisable between death of the IDS-TILDA participant and eligibility for inclusion in the End-of-Life Care study. This was to ensure that emotional distress was minimised as far as possible by ensuring that the timing for recruitment was appropriate, and also to ensure that the risk of acute grief impacting on ability to provide voluntary, informed consent was minimised. Previous research has indicated that a 6-month time period between bereavement and recruitment is advisable [167] and this approach was adopted.

Management of risk during consent process

In addition to considering the timing of the consent process, potential respondents were provided with clear, Plain English information and consent forms in the contact letter, together with contact details of the research team. This was to provide indviduals with time to read and consider the material, in advance of the opportunity to discuss the study. Important information was repeated immediately prior to participation in the interview (e.g., freedom to stop or opt out at any time) and verbal consent was again sought.

Management of emotional distress

A risk management protocol was designed to manage any potential distress based on best practice in the field. Training was provided to all interviewers. The well-being of respondents was recognised as paramount and was at all times be prioritised over data collection. Respondents were encouraged to schedule the interview at a time, place, and format most convenient and comfortable for them. The interview began with rapport-building questions, and as the interview progressed, more emotionally sensitive questions were asked as appropriate. Reminders of the right not to answer specific questions if they would prefer not to are highlighted throughout the interview, providing reassurance to the individual that they are not under any pressure or obligation to participate. Support in the form of referral to, and assessment by, a clinician was available in the event of respondents experiencing severe distress (this was not, however, required by any interviewee). A telephone number was included on the respondent information leaflet for respondents to contact the project team at any time before or after the interview, if required. The person answering the call was trained to respond sympathetically to any callers and to direct their query to the appropriate person in the study team. For the interviewers, debriefing and feedback was conducted regularly to maintain the well-being of interviewers and the continuance of a culture of high reliability and safety.

Management of confidentiality

The management of confidentiality in qualitative research requires attention to the appropriate use of rich descriptions and direct quotes in support of research findings. This is particularly pertinent when dealing with sensitive topics where identification of respondents could lead to harm. To address this risk, pseudonyms were used for respondents, and defining characteristics altered to protect anonymity. In addition, comprehensive training in data protection and research integrity is provided to IDS-TILDA researchers to ensure the highest standards of ethical conduct are maintained.

3.6 Sample

Baseline data collection for IDS-TILDA began in 2009. [4] The original sample recruited at Wave 1 consisted of 753 people with an ID aged 40 years and above. Subsequently, 708 participants took part in Wave 2 and 609 remained in Wave 3. Data collection for the End-of-Life Study began during Wave 2 data collection as it was identified that a number of IDS-TILDA participants had died.

An invitation pack to participate in the IDS-TILDA End-of-life Care study was extended through the relevant ID organisation to primary carers of the decedents who met study eligibility criteria (Table 9). The invitation pack included the study questionnaire and consent materials. Potential respondents receiving the invitation pack were encouraged in the accompanying letter to read the study material and the consent materials. If they were willing to participate in either or both of the survey and interview, they were offered opportunity to discuss the study further with the research team, were requested to sign the consent form and return it in the enclosed stamped, addressed envelope together with the completed survey. Contact was subsequently made to arrange time for interview and verbal consent was again established prior to the interview.

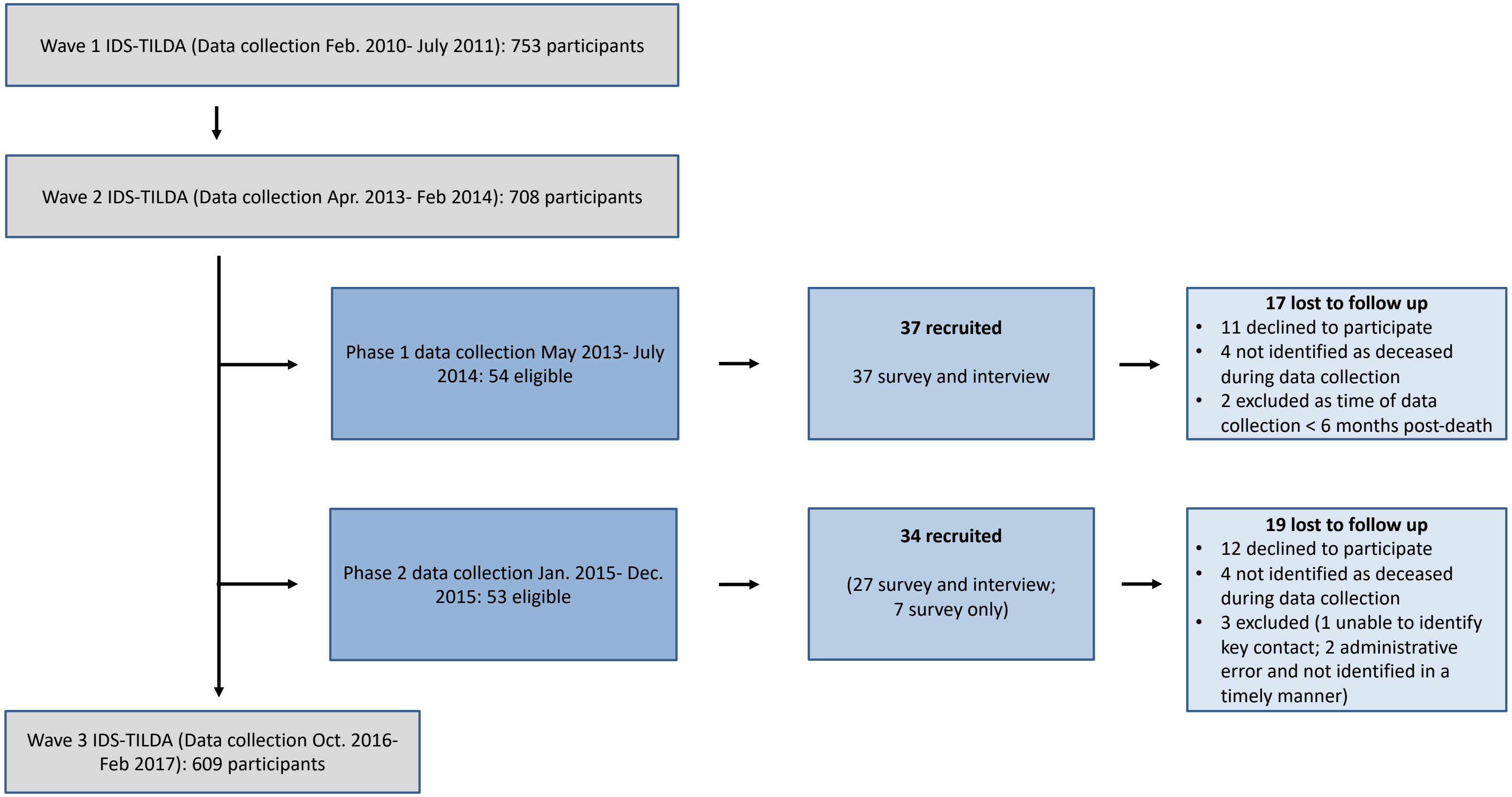
Table 9 Inclusion and Exclusion Criteria

Inclusion criteria	**Exclusion criteria**
Provided direct physical care and/or emotional care in the last year of life	Did not provide direct physical care and/or emotional care in the last year of life
Knew and cared for the person who died for at least 1 year	Knew and cared for the person who died for less than 1 year
Knew the person well, including their personal, health and social circumstances and preferences in this time	Did not know the person well, including their personal, health and social circumstances and preferences in this time
Family member, friend, paid ID staff member, healthcare provider, volunteer care provider	Not a family member, friend, paid ID staff member, healthcare provider, volunteer care provider
The person died at least 6 months ago	The person died less than 6 months ago

In total 107 deaths were identified as occurring by Wave 3. Data collection for the End-of-Life Care study took place during Wave 2 and Wave 3; 37 respondents were recruited during Wave 2 and

34 respondents were recruited during Wave 3. Over the course of data collection, 71 bereaved carers completed surveys and 54 participated in qualitative interviews. See Figure 4, recruitment flow chart.

Figure 4 Recruitment flow chart for end-of-life care study



3.7 Data collection

Given that the IDS-TILDA End-of-life Care Study is a convergent parallel mixed methods study, quantitative and qualitative data collection was conducted concurrently in two phases.

The quantitative database comprises responses to the IDS-TILDA End-Of-Life Care survey. The qualitative database comprises interviews given by consenting caregivers. The interviews use the IDS-TILDA End-of-Life Care survey as the basis for the topic guide; the interviews additionally use explanatory comments and probes to seek increased clarification and understanding. Axinn and Pearce [168] note that merging databases works best if parallel questions are asked in both phases, thus enhancing the 'comparability of questions' (p74) and facilitating the comparison of results across concepts. While the two databases are independent, each standing on its own, the data also captures different facets of the individual's life and death. In this way both triangulation of data is possible (producing corroborated and valid conclusions) and the generation of new insight and understanding.

In the study design phase, care was given to evaluating how concepts of interest mapped to candidate survey instruments to ensure that the selected survey would address topics of relevance to the research question and comparability of questions across datasets. This led to Views of Informal Carers- Evaluation of Services Short Form' (VOICES-SF) being selected as the basis for the End-Of-Life Care survey instrument. [169]

End-of-life Care survey instrument

The 'Views of Informal Carers- Evaluation of Services' (VOICES) questionnaire is a bereaved carers survey that was based on a shortened version of the interview schedule used in the Regional Study of Care for the Dying. [170] The original VOICES questionnaire contained 158 questions printed on 28 pages. It had advantage over other bereaved carer instruments in that it was designed to assess patient and family experiences of care across different settings and providers over the last three months of life. The VOICES questionnaire is a survey instrument rather than a psychometric scale, and as such, validation was ensured by following the principles of good questionnaire design and testing rather than psychometric testing. This included cognitive and pilot testing of new questions.

VOICES-SF is a shortened and modified form of VOICES. It was developed by the University of Southampton in 2010 in response to the desire of the Department of Health for England to monitor the outcomes of the End-of-life Care Strategy [171], [172] from the service user's perspective.

The original content of VOICES was based on patients', bereaved relatives', and healthcare professionals' views about what is important at the end-of-life. Content was modified in VOICES-SF to include measures that would provide insight into the impact of the End-of-life Care Strategy. New questions were therefore added focusing on such issues as preferred place of death, breaking bad news, needs assessment and co-ordination of care. Old, redundant questions were removed.

VOICES-SF takes about 30 minutes to complete and is administered by postal survey. It comprises 58 questions and features a combination of question formats, including 4-point rating scales, multiple choice, and opened-ended items. The survey reviews different time periods, such as the last three months of life, the last two days of life, and circumstances surrounding the death. Data is collected on topics such as symptom management, communication, respect and dignity and care provided. Questions are repeated across settings to allow for cross-comparison. The survey ends with two open-ended items asking what, if anything, was good about care, and bad about care. The question content includes an overall rating score for care in the last 3 months of life, an overall rating for each specific setting, and ratings for particular domains of quality, such as pain management.

The End-of-Life Care survey instrument used in this study represents an adapted version of VOICES-SF. The first modifications that were made to VOICES-SF were carried out to make it suitable for administration in the Irish setting:

- The list of settings included in the survey was expanded to include intellectual disability service settings given the specific focus of this study.
- The term 'usual home' was used instead of 'home' in recognition of the fact that decedents may have split time between family home settings and residential care settings. Establishing the person's usual home allowed the baseline home location of the person to be determined.
- The terminology used to describe health and social care professionals working in the Irish setting was altered to reflect Irish nomenclature and roles e.g., public health nurse, Irish Cancer Society night nurse, community intervention team.

After administration of the survey to nine respondents and preliminary data analysis, further modification was made in the form of the addition of 12 further questions. Six items from the TILDA exit interview [173] were added to increase opportunities for comparisons with the general older population in Ireland. Six items were added on post death rituals based on the large amount of data emerging on this topic from the initial interviews. Appendix 2 contains the final version of the survey instrument.

Mode of administration

Bereaved carer surveys have been administered in a variety of formats- postal, electronic, and interview-based. Addington-Hall et al. found similar response rates between postal and interview-based surveys;[174] Hunt et al. found that the online version of the questionnaire was used primarily by the 'opt in' group surveyed, where respondents used the online version to bypass the need to request a paper copy of the survey.[175] It appears that both postal and interview methods are generally acceptable to respondents. As a result, postal interviews have been utilised most widely as they are considerably cheaper and require fewer trained staff to administer.

It cannot be assumed that these experiences can be extrapolated to the intellectual disability setting. For this reason, the End-of-Life Survey was administered in in-person interview format for the first nine respondents. Following initial analysis and consideration of participant feedback, a decision was made to change to postal administration of the survey followed by the qualitative interview. This decision was made based on feedback that respondents invested time in considering the responses to the survey questions and benefitted from completing a paper-based survey on their own. Conducting the qualitative interview subsequent to the paper-based survey allowed for a richer discussion then to be had in which there was opportunity to speak about the deceased and discuss issues that had arisen during completion of the survey. Respondents were offered the option of either in-person or phone interview and additional ethical approval was sought and obtained for amendments to the original research ethics approval to allow for these changes to the protocol and for audio recording of interviews.

3.8 Analysis

Four major steps have been described in convergent design.[156] First is data collection which occurs concurrently but separately, next is analysis of the datasets which also occurs separately using qualitative and quantitative procedures. Third is the point of interface or convergence where the results of the two datasets are merged. In this study, side-by-side comparison[143] was conducted during the convergence phase and study findings are presented in chapter 4 as passages organised by major topics with presentation of quantitative data preceding qualitative data. In the fourth step, interpretation of data is carried out to generate knowledge on the extent and ways in which the two sets of results converge or diverge, are complementary or contradictory, and/or combine to create a more comprehensive understanding of the topics at hand. For example, the subjective perceptions of different survey and interview respondents will be compared with IDS-TILDA observational data to corroborate or contextualise observed phenomena and to highlight discrepancies between various stakeholder impressions and objective third-party observations.

Quantitative data analysis

Data management and statistical analyses for quantitative data were conducted with IBM SPSS for Windows, version 26. Statistical significance was defined at the 0.05 level. Descriptive statistics were used to identify participant characteristics and to compare data distribution across groups and between time periods (IDS-TILDA Wave 1 and the End-of-Life Care Study). Non-parametric comparison tests on two or more independent and dependent samples were used to assess differences between groups.

Qualitative data analysis

Following interview transcription and anonymisation, qualitative data were managed in NVIVO 12 and analysed using Braun and Clarke's six steps of thematic analysis: 1) transcripts and fieldnotes were read and re-read to ensure familiarity with the data 2) initial codes were generated 3) codes were then collated into potential themes 4) themes were reviewed to ensure they worked in relation to the coded extracts and entire dataset 5) ongoing analysis was conducted to define and name the themes 6) write-up offered a final opportunity for analysis and refinement. [176-178]

The process of coding and thematic analysis incorporated both the data-driven inductive approach of Boyatzis [130] and the deductive a priori template of codes approach outlined by Crabtree and Miller. [131] This approach complemented the research questions by allowing the findings of the integrative literature review (chapter 2) to be integral to the process of deductive thematic analysis while also permitting themes to emerge direct from the data using inductive coding.

Audit trails, peer debriefing and researcher triangulation enhanced transparency and credibility of the process. Rigour was promoted by critical comment on interpretations and systematic use of data extracts to illustrate themes.

3.9 Strengths and limitations

The mixed methods methodology adopted offers opportunity to harness strengths that offset the weaknesses of quantitative and qualitative research. [156, 179] In this study, the qualitative data illuminate areas of corroboration and divergence and provides additional understanding of survey data that is more than the sum of two parts- ensuring that questions are answered in a more satisfactory or comprehensive way that would be possible if only quantitative or qualitative perspectives were utilised. The two datasets provide opportunities for corroboration and validation, illustrating qualitative findings with quantitative results (or vice versa). Moreover, a mixed methods approach encourages the use of multiple worldviews and typically combines inductive and deductive logic through abductive thinking. [158] It has been observed that mixed methods is both practical and intuitive as it offers multiple ways of viewing problems [156] and this may help knowledge transfer given that this is an approach to problem-solving often taken in real-world settings.

While the qualitative interview collection allows the voice of carers to be directly heard and a detailed understanding of the experiences of end-of-life care to be generated, an important limitation of this study is the fact that responses mainly represent the perspective of ID staff rather than family members, and that the direct voice of the person with an intellectual disability is not heard.

The longitudinal nature of IDS-TILDA affords opportunity to understand how experiences and relationships change over time and offers a robust sampling framework for the End-of-Life study that supports generalisability of findings. However, the utilisation of the IDS-TILDA study, also means that the sample is drawn from people over 40 years of age only and the sample size is limited to those deaths that occur among those enrolled in IDS-TILDA. The current sample size has limited the possibilities for analysis, although it is expected that the sample size will increase with time.

It is also worth noting that data collection occurred over two waves and time between death of the person with an intellectual disability and carer interview varied significantly. There is little evidence to base decisions on when is the optimal time to conduct interviews but it is possible that recall may be influenced by time. [175] The individual interview was a valuable way of collecting rich data to supplement the paper-based VOICES-SF questionnaire and it is hoped, also served to mitigate the possibility of sub-optimal data collection.

A final consideration is that the two databases are limited by practical constraints of data collection i.e., due to the size of the sample, a prioritised number of datapoints only could be collected. This means that while there is advantage in having datasets of equal size to facilitate data collection, some of the richness of qualitative data collection was sacrificed due to time and resource constraints.

Chapter 4. Results

4.1 Survey data

4.1.1 Decedent demographics

Of the 753 individuals who were enrolled in IDS-TILDA, 14.2% (n = 107) were known to have died by end of Wave 2 data collection (Figure 4). Just over half of decedents were female (53.3%; n = 57) and the majority had moderate (46.7%; n = 50), or severe/ profound levels of disability (37.4%; n = 40). Only 8.4% (n=9) decedents had mild intellectual disability. Most commonly, decedents lived in residential care settings (71%; n = 76) prior to death. While 20.5% (n = 22) of deaths occurred in those younger than 50 years of age, 41.4% (n = 44) were between 50-64 years old, and 38.3% (n = 41) were aged 65+ years.

The characteristics of the 71 decedents included in the IDS-TILDA End-of-Life study sample are also shown in Table 10. Chi-squared tests of the equality of proportions were conducted to see if there were significant differences in the demographic characteristics of those decedents whose caregivers were enrolled in the End-of-Life component of IDS TILDA and those decedents whose caregivers did not take part. No significant differences by age of enrolment, gender, level of ID and place of care of the person with an intellectual disability were observed. Of the sample of 71 decedents, 57.7% (n=42) were female, and the majority had a moderate (45.1%; n=32) or severe (38%; n=27) disability. Nearly three-quarters (73%) of the End-of-Life sample lived in residential care.

4.1.2 Respondent demographics

Most respondents were female (56.3%) and were intellectual disability staff (ID staff) members (94.3%). Staff generally had long and close relationships with decedents; the average length of time that staff knew the decedent was 11.3 years (1-39; SD 11.3) and 63.4% (n = 45) worked directly in the decedent’s home (Table 10).

Table 9 Characteristics of participant and non-participant decedents and respondents drawn from IDS-TILDA

Variable	Participants in both IDS-TILDA and the End-of-Life Care Study		Participants in IDS-TILDA only (i.e., non-participants in the End-of-Life Care Study)		X^2
	n	%	n	%	*P*-value
Decedent gender					
Male	30	42.3	20	55.6	0.19
Female	41	57.7	16	44.4	
Decedent level of ID					
Mild	7	10.6	2	5.6	0.87
Moderate	32	45.1	18	50.0	
Severe/ profound	27	38.0	13	36.1	
Missing	5	7.0	3	8.3	
Residence[8]					
Family/ independent	2	2.8	5	13.9	0.09
Community group home	17	23.9	7	19.4	
Residential care	52	73.2	24	66.7	
Decedent age					
<50	14	19.7	8	22.2	0.75
50-64	31	43.7	13	36.1	
65+	26	36.6	15	41.7	
Respondent gender					
Male	5	7.0			
Female	40	56.3			
Missing	26	36.7			
Respondent relationship to decedent					
ID staff working in the decedent's home	45	63.4			
Keyworker	13	18.3			
ID staff working outside the decedent's home	9	12.7			
Relative	3	4.3			
Other[9]	1	1.4			

4.1.3 Comorbidities, perceived duration of illness, cause of death

Comorbidities

Table 11 provides data on comorbidities, cause of death and perceived duration of illness. At wave 1, just over one-half of decedents (52.9%; n = 37) were reported to have had known diagnoses of mental health disorders. Neurological disorders were the most common physical disorder- just over one-fifth (22.9%, n = 16) had dementia, while one third had a seizure disorder (33.8%, n =

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[8] As recorded in IDS-TILDA Wave 1

[9] Both a family member and ID staff member provided interviews for one decedent

24), and just under one-fifth (19.7%, n = 14) had other neurological diagnoses such as spina bifida, cerebral palsy and Parkinson's disease. Cardiovascular disease was also common with nearly one-half of the participants (48.6%, n = 34) having a diagnosis of hypercholesterolaemia, hypertension, arrhythmias, valvular or ischaemic heart disease. About one-third of participants had an endocrinological disorders, with 14.3% (n = 10) having diabetes and 16.9% (n = 12) having a thyroid disorder. Chronic lung disease was reported as affecting only 12.7% (n = 9) of participants at Wave 1 and cancer was uncommon, affecting 4.4% (n = 3).

As might be expected, an increasing number of comorbid illnesses were reported in the End-of-Life Care Study. The most common new diagnoses to be made were neurological (16.4%, n = 11), cancer (16.2%, n = 11), respiratory (11.8%, n = 8) and psychiatric cancer (10.3%, n = 7).

Length of illness prior to death

Survey data revealed that 4.2% (n=3) of people with an intellectual disability died suddenly and unexpectedly, having been perceived by respondents to be well prior to death. Two of those deaths were due to cardiac events, and the cause of the remaining death was not known despite post-mortem. While sudden deaths occurred in a minority, 26.8% (n = 19) of decedents were perceived to have had a short illness duration and were reported as being unwell for a period of one month or less. Staff reported that 40.8% (n = 29) had experienced a relatively lengthy decline where decedents had been unwell for six months or more.

Data on cause of death is characterised by a significant proportion of missing data (18.3%, n = 13) as respondents often stated that they did not know the exact cause of death. The three most common reported causes of death all accounted for similar proportions of deaths- respiratory disease reportedly accounted for 22.5% (n=16) of deaths, while cancer accounted for 19.7% (n=14) and dementia for 18.3% (n=13).

Table 10 Comorbidities, illness duration, cause of death

Variable	n	Valid Percent
Comorbidities at wave 1 data collection		
Mental health disorder	37	52.9
Cardiovascular disease	34	48.6
Down Syndrome	24	33.8
Alzheimer's or dementia unspecified	16	22.9
Other neurological condition	29	40.8
Endocrinological disorder	21	29.6
Gastrointestinal disorder	24	33.8
Chronic lung disease	9	12.7
Cancer	3	4.4
Additional comorbidities reported at End-of-Life Care Study	**n**	**Valid Percent**
Mental health disorder	7	10.3
Neurological condition	11	16.4
Cerebrovascular accident	1	1.5
Endocrinological disease	4	5.9
Lung disease	8	11.8
Cardiovascular disease	5	7.0
Gastrointestinal disease	6	8.6
Cancer	11	16.2
Length of time unwell before death	**n**	**Percent**
She was not unwell- she died suddenly and unexpectedly	3	4.2
One day or more, but less than one week	7	9.9
One week or more, but less than one month	12	16.9
One month or more, but less than six months	20	28.2
Six months or more but less than one year	13	18.3
One year or more	16	22.5
Missing	0	0
Cause of death	**n**	**Percent**
Respiratory	16	22.5
Cancer	14	19.7
Dementia	13	18.3
Circulatory	6	8.5
Renal	4	5.6
Gastrointestinal	3	4.2
Neurological (not dementia)	2	2.8
Missing/ not known	13	18.3

4.1.4 Care transitions in the last year of life

Respondents were asked to state where the decedent's 'usual home' was, and they were also asked whether the person's place of care had changed in the last year of life (Table 6).

Nearly a quarter usually lived in community settings (22.4%; n = 24) and only 6.5% (n = 7) were recorded as living in independently or in family homes. Home environments were commonly supported with nursing and other staff; 64.8% (n = 46) had full-time social care staffing and 53.5%

(n = 38) had full-time nursing staffing. The mean number of fellow residents was 7.23 (1-20, SD 11.32) and 23.9% (n = 17) of decedents shared a bedroom. Although 91.5% (n= 65) of residences had bedroom(s), bathroom, and kitchen all on the same level, 33.8% (n= 24) of decedents had difficulty getting around their home.

In the last year of life, 15.5% (n = 11) of service users moved home; four moved out of the ID service to nursing homes, while seven remained within the ID service but moved to higher support units there. Service users were noted to have increased care needs that could not be met in their usual place of care for a variety of reasons. These included the need for increased staffing numbers or for staff with healthcare competencies, and the need for more suitable environments (where equipment such as hoists could be used, or where care of the individual did not impact on other residents). In three cases, respondents cited lack of funding as a reason for being unable to put the necessary support in place to maintain the person with an intellectual disability at home.

Table 11 Usual place of residence, care transitions and place of death

Variable	n	%
Usual place of residence		
Family/ independent	2	2.8
Community group home	17	23.9
Residential care	52	73.2
Level of staff support (excluding nursing staff) in usual place of residence		
24 hours a day	46	64.8
Part time	20	28.2
No support staff	5	7
Level of nursing support staff in usual place of residence		
24 hours a day	38	53.5
Part time	18	25.4
No nursing staff	15	21.1
Level of difficulty getting around his/ her home?		
No difficulty	47	66.2
Some difficulty	8	11.3
A lot of difficulty	7	9.9
Cannot do at all	9	12.7
Place(s) of residence in last year of life		
Remained in residential setting	42	59.2
Remained in community group home	10	14.1
Remained in family/ independent setting	4	5.6
Remained in nursing home	2	2.8
Moved to higher support setting within residential care	3	4.2
Moved from community group home to residential setting	5	7.0
Moved from community group home to nursing home	2	2.8
Moved from residential setting to nursing home	1	1.4
Other W166	1	1.4
Missing W228	1	1.4

Place of death		
ID organisation (people with an intellectual disability)	36	50.7
Hospital	27	38
Hospice	5	7
Nursing Home	2	2.8
Home of another family member or friend	1	1.4
Other	0	0
Missing	0	0

4.1.5 Service utilisation in the last year of life

Survey data demonstrated that overall, service use increased in the last year of life in comparison to those recorded at Wave 1, although some services were used more commonly than others (Table 12). In keeping with the fact that most respondents lived in residential care settings, use of community-based services such as public health nursing and Home Support Services (homecare assistants who provide support for everyday tasks such as personal care) was low at 13.2% (n=9) and 2.9% (n=2) respectively. Over half the decedents received religious support and input.

Hospital admissions in the last year of life were common, and 69.1% (n = 47) of decedents were hospitalised on at least one occasion.

Specialist palliative care (SPC) services were accessed by 40.8% (n=29) of decedents. Of the services accessed, 32.3% (n=23) decedents received community palliative care (CPC) only, 4.2% (n=3) received CPC and in-patient hospice care, and 4.2% (n=3) received in-patient hospice care only. Of those receiving SPC, just over half (55%) had a non-malignant diagnosis.

Table 12 Services accessed in the last year of life by decedents living outside of nursing homes.

Service accessed	IDS TILDA Wave 1		End-of-life Care Survey		X^2 / Fishers exact
	n	**%**	**n**	**%**	***p*-value**
Public health nurse					
Yes	5	7.4	9	13.2	0.25
No	63	92.6	59	86.8	
Missing	0	0	0	0	
CPC Nurse *					
Yes	7	10.3	26	38.2	<0.01
No	61	89.7	38	55.9	
Missing	0	0	4	5.9	
Home Support Services					
Yes	0	0	2	2.9	0.25
No	68	100	66	97.1	
Missing	0	100	0	100	
Social Worker					
Yes	18	26.5	30	44.1	0.02
No	50	73.5	36	53.0	
Missing	0	100	2	2.9	
Psychology/ counselling					
Yes	19	27.9	17	25.0	0.70
No	49	72.1	51	75.0	
Missing	0	0	0	0	
Religious support					
Yes	N/A	N/A	42	61.8	
No	N/A	N/A	23	33.8	
Missing	N/A	N/A	3	4.4	
Occupational Therapist					
Yes	23	33.8	39	57.4	<0.01
No	45	66.2	29	42.6	
Missing	0	0	0	0	
Physiotherapist					
Yes	30	44.1	39	57.4	0.12
No	38	55.9	29	42.6	
Missing	0	0	0	0	
Speech and Language					
Yes	26	38.2	38	55.9	<0.01
No	42	61.8	21	30.9	
Missing	0	0	9	13.2	P=0.003
Dietitian					
Yes	29	42.6	37	67.6	P=0.03
No	39	57.4	23	33.3	
Missing	0	0	8	11.8	

4.1.6 Place of death

Most people with an intellectual disability (50.7%; n=36) died in a place of care within the ID organisation. Hospital was the next most common place of death (38%; n=27); followed by hospice (7%; n=5) and nursing home (n=2; 2.8%).

Respondents reported that the ID organisation was the right place to die for those decedents who received end-of-life care there, except for one case where the respondent was '*not sure'*. Respondents unanimously agreed that the hospice was the right place of death for those individuals who died there. However, there were mixed opinions about hospital as a place of death- in 54.2% of cases, the respondent felt it was the right place; in 25% they were unsure; and in 20.8% they felt it was the wrong place to die.

Overall, 60.5% of those who were not receiving community SPC died in hospital, while only 19.2% of those who were receiving community SPC died in hospital (X^2(1, N=69) = 11.1, p =0.001).

4.1.7 Satisfaction with service provision

Satisfaction with the adequacy of service provision was high (Table 13). Overall, 86.2% (n=56) of respondents felt that services worked well together and 80% (n=52) felt that they received as much support as they needed from general health services (i.e., services external to the ID organisation). Satisfaction with the adequacy of supports provided internally from ID-based services was lower at 73.8% (n=48).

In all cases where decedents received in-patient care in the palliative care unit, it was reported that staff always treated the person with an intellectual disability with dignity. In 83.3% (n=5) cases, it was reported that pain was controlled 'completely, all of the time'. In one case, it was reported that pain was controlled '*completely, some of the time*'. Overall, the quality of care was rated as '*excellent*' in all cases.

Taking all things together, respondents felt that the quality of care provided at the end-of-life was of high quality. Overall, of valid responses, 70.3% (n=45) rated it as excellent, 25% (n=16) as very good or good, with only one response each of 'fair' and 'poor.

Table 13 Satisfaction with services provided

Services work well together	n	%
Yes, definitely	56	86.2
Yes, to some extent	5	7.7
No, they did not work well together	2	3.1
He did not receive any care	1	1.5
Don’t know	1	1.5
Missing	0	0
Enough help health and social care support from ID organisation		
Yes, we got as much support as we wanted from ID	48	73.8
Yes, we got some support, but not as much as we wanted	8	12.3
No, although we tried to get more help	5	7.7
We did not need help	3	1.5
Missing	3	4.6
Enough help health and social care support from external services		
Yes, we got as much support as we wanted from	52	80
Yes, we got some support, but not as much as we wanted	3	4.6
No, although we tried to get more help	1	1.5
We did not need help	2	3.1
Missing	7	10.8

Note: N=65 as survey instructed respondents to skip these questions if the person with an intellectual disability died suddenly with no illness or time for care (n=3), or if the person was in a nursing home for the last three months of life (n=3)

4.2 Interview data

4.2.1 Palliative care needs of the person with intellectual disability

In keeping with the typology of palliative care needs identified in Chapter 2’s integrative literature review, individuals who experienced a period of recognisable illness before death were noted to experience needs in a variety of domains.

Time and continuity of care needs

Time and continuity of care were viewed as necessary to establishing a therapeutic relationship where a person with intellectual disability would trust healthcare professionals and where those providing care would ‘know’ the individual:

> *'He had the benefit of being with a lot of staff that knew him a long time. And you know, as you know a person for a long time there will be little bits that you can never maybe write down or that… but you know.'* (W504)

For the person with intellectual disability, continuity of relationship ensured trust and comfort:

> *'But it's still someone they know, and are familiar with, and comfortable with. And they know what you're going to do, and how you're going to react, and there's no surprises.'* (W509)

It was often difficult for people with an intellectual disability to engage with clinicians without an established relationship. One staff member explained how this helped a decedent engage with a visiting doctor, *'And she would have been quite wary of doctors. But I suppose over time she built up a relationship with Dr. Brown [usual doctor working in the ID service] and she was fine.'* (W191)

'Knowing' the individual and having that relationship was important because it was felt to be an essential first step in being able to recognise and respond to the person's needs. Without that, interviewees commented that clinicians could miss signs of distress:

> *'She said 'Joan, I'm so frustrated here." She said "I follow him to the toilet and he's not able to do this and that. And I've said to the doctors he's in extreme pain. And they're saying to me he's not". And she fought tooth and nail and [the doctors said] "He couldn't be in pain that what we've given him is right." She said, "I can see it in him, he's not well, he's in pain."'* (W025)

Physical and personal care needs

Pain and symptom control was made more complex by challenges assessing distress in a person with cognitive and communication impairment. As a participant explained, assessment was '*very hard, because she couldn't tell us'* (W003). Conversely, there were situations where acquiescence could mean that *'99.9% of the time, she'd say "Yeah, I have pain"'* (W114). At such times, a combination of subjective report and objective assessment was needed in order to judge whether it was best to administer analgesia or whether an alternative non-pharmacological response was preferable. A participant explained the importance of an individualised approach that involved the input of the team:

> *'With people with ID is that- I find anyway- sometimes if you ask them the question, they'll give you back the answer that they perceive that you want. So, if you say, "Have you got*

> *pain?" [then they will respond] "Yes, I have pain" … You kind of have to- each individual person- you kind of have to figure out a way and come together. And kind of come up with a consensus of how it is.'* (W006).

It appeared that life-long experience of disability further complicated matters because it was felt that people with intellectual disability often experience chronic pain. Expectations regarding management of pain and expression of pain could be muted:

> *'They learn to live with a certain level of pain. Especially if they've autism or they have a dementia. And they have a huge threshold. So that what me and you would experience as pain and we would react to it, they don't 'cos that's the normal way they feel.'* (W025)

To address communication difficulties, the routine use of assessment tools was widespread, and staff regularly looked for non-verbal signs such as *'vocalisations'* and '*facial expressions', 'mood change' and 'body language' (W035).* Keeping a record of the individual's personal language of distress was felt to be helpful and it meant that *'if there was staff on that didn't know them that well, they'd be able to tell like from the chart, like, what's going on with that person'* (W027). The SPC team was recognised as a resource to support the management of refractory pain:

> *'Because she had been in a lot of pain and discomfort. No matter what you done. If you, you know, got her up, or put her into bed, twisted or turned her. You'd try anything to make her comfortable. And nothing was working. So, they did ring the palliative care team.'* (W171)

Family could also be an important support and resource in assessment and management:

> '*And that's where the family came in because they were able to read (and maybe Liz being a private person) they were able to say, "I know she's in pain, I think we should talk to the palliative care team, and we should change her meds."'* (W779)

Sometimes challenging situations could arise where staff felt that medication was necessary to maintain wellbeing but the person with intellectual disability was reluctant to take analgesia and lacked capacity to make an informed decision. In such situations, the importance of ensuring comfort appeared to be the dominant influence on practice:

> *'And in the end, we compromised with the palliative care team, and herself, and her GP and giving her regular painkillers. Because she just, she always denied pain that we see in her sometimes- from her demeanour, or the way she was moving, or whatever. But … so,*

> *we agreed she would take regular painkillers. So that we wouldn't have to keep harassing her and drawing her attention to it. And so that she could have relief.'* (W750)

It is important to note that not all individuals with intellectual disability experienced difficulty in communicating distress or participating in self-management. The following quote illustrates the experience of an individual who was able to engage effectively:

> *'And again, as I say, she was very, she would've been very pro-active herself. If she said she had a pain, you could take it on the basis that she had pain, you know.'* (W114)

Reassuringly, most bereaved carers felt that comfort was achieved in pain and symptom management. A variety of pharmacological and non-pharmacological approaches were commonly used to ensure comfort:

> *'I suppose we used a multi-element, a multi-factorial element. We used pain relief, but we also used alternative therapies and relaxation techniques as well, and that seemed to work for Owen.'* (W119)

Emotional, psychosocial, and spiritual needs

In keeping with Dame Cicely Saunder's conceptualisation of 'total pain', people with intellectual disability experienced emotional distress directly or indirectly related to life-limiting illness. One participant described emotional changes observed in an individual that were felt to be directly related to illness:

> *'Like all his anger and all that and that lashing out, that was there before, you know, that was, we felt it was more down to the personality change that came with the vascular dementia more so than through the pain.'* (W440)

Another described how pain led to low mood and highlighted the challenge involved in differentiating between cause and effect in people with intellectual disability:

> *'We thought that maybe the depression was a sign of pain, that he was quite down, and sometimes the facial expressions…. But that was our only way of judging it because … he would never tell you.'* (W014)

A range of emotional responses were evident that included anger, low mood, anxiety, and fear. Loss of independence and difficulty understanding reasons for change could lead to significant distress:

> *'I wouldn't say he was depressed- I'd say he was more, more angry at himself, and confused- even though he had and got our reassurance. I think he was still like "Why, what's happening, why am I this way?" … I think he… he… yeah, his agitation stemmed a lot from that, you know, because he... he couldn't get to do what he was so independent in doing…'* (W699).

Positive adaptive responses to illness were also observed, and some respondents felt that the life-long experience of disability facilitated adjustment and coping:

> *'We'd another young man that got motor neuron disease and like we thought, "Oh my God, when he loses his walk it's gonna be so hard on him" because he was so independent, but no, they're just so accepting. They really amaze you.'* (W019)

As counterbalance, another participant cautioned against overly romanticised views of individual acceptance of illness and pointed to the legacies of institutionalisation:

> *'I think the fact that he is so accepting, you know, maybe in years to come when we're doing this sort of research and because people won't have been put into institutions and had institutional-type care where staff happened to them regardless of… You know, when people have more choices about their lives, we'll probably get a different picture maybe from them.'* (W509)

Psychosocial needs

The value of social networks and engagement was noted in meeting the emotional needs of people with intellectual disability and serious illness:

> *'He wasn't put on any medication, he wasn't, no it was kind of managed with maybe more outings, more family visits, which was what he needed.'* (W739)

Respondents commented ~~on how~~ that being engaged with others and busy was of help as a coping strategy:

> *'She'd a great relationship with one of the household. She'd always ask about her kids … stuff like that… I think it kept her busy, her mind busy, I got the sense that she didn't, she wasn't wallowing in what was going on. Although she did know she was very unwell.'* (W114)

High value was placed on accompaniment and relationship-based care in meeting the emotional needs of people with intellectual disability. A participant explained how this helped one resident:

> *'…her family would have been in regularly. And as I say, like, the staff knew her so well, they'd just sit chatting to her… So, from that point of view, I think she was very content.'* (W114).

Spiritual needs

As with the general population, people with intellectual disability religion and spirituality were reported as placing varying importance on religion or personal spiritual beliefs. While the historical influence of the religious bodies that had originally provided services was still evident, residents were afforded choice and autonomy with regards to practice: *'As far as I know, all the residents here are Catholic. And not all are practicing, but he would always have gone to any sort of masses.'* (W377).

For many, it appeared that family values played a large role in shaping religious practice:

> *'There was a hospital chaplain that came and prayed with him. I think everyone is our family is religious, so that was useful, and he used to go to mass, so that was nice… he would have liked that, yeah.'* (W143)

However, ultimately it appeared that individual characteristics led to whether a person found religion to be an important part of their lives of not. The following excerpt illustrates how spirituality was regarded as an essential characteristic of some:

> *'She was quite holy. She always attended mass and stuff in her day like kind of thing. And some of the girls wouldn't be now, but yeah, no, she definitely was. Kind of religion was part of her.'* (W201)

Another staff member recounted how it was not possible to support a resident who was living in a house in the community to attend mass in the local church due to resource constraints, but how the person continued to practice by watching the weekly mass on tv and listening to the local radio:

> *'Because they had the radio set for the local thing, brought in, turn on the telly … he loved it, whereas before he used to go to mass every Sunday.'* (W700)

Sometimes ID staff found it hard to judge whether or not a person with intellectual disability understood what they were engaging with. As a staff member commented:

> *'She would go to mass. And actually, she knew … the word "heaven". But whether she actually understood what it was … It's hard to say … you know.'* (W207)

Nonetheless, there was a sense that those individuals who did go to mass or who prayed obtained comfort or a sense of community from their practice. It appeared that ID staff recognised the importance of this dimension of care, and there were examples of ways in which the staff endeavoured to respect and support the individual's faith at times of serious illness:

> *'And they did say before she went to the hospital that they said prayers. That's just coming into my head now that they did say prayers while they were waiting for the ambulance. They were holding her hands and saying prayers together.'* (W750)

Communication needs

As previously noted, management of distress needs was felt to be challenging in the setting of impairments of cognition and communication. As a fundamental starting point, participant opinion about whether people with an intellectual disability recognize when they are seriously ill varied. While individuals with more severe disability were often regarded as unlikely to be aware of serious illness, there was acknowledgement that people with mild intellectual disability could have more insight, regardless of whether the individual had been told of their condition or not. A staff member spoke of the experience of witnessing the decline of a resident, *'Because it was her own physical health deteriorating. And, yeah definitely, she knew, she knew.'* (W114)

ID staff commonly displayed a mindset that placed value on lived experience and emotional intelligence as ways in which people with intellectual disability engage and understand the world. As one participant explained:

> *'And she'd tell you "My mum's dead". You know, like she knew what dead was, you know, I mean she would've been quite low-level IQ-wise. But she had good understanding and loads of common sense. And she'd gown up with a family and she'd good family experiences.'* (W457)

This added to the complexity of judging whether an individual was aware of the significance of their deteriorating condition or imminent death because staff felt it was possible that even when people weren’t told of their illness or had severe or profound disability, they might have developed some level of awareness of change:

> *‘And I remember I was on that Sunday, and he was doing different gestures that he would ever do before. He would be blessing himself. He‘d hold your hand. I remember my mobile rang- he was more or less gesturing “Put that…”. You know- to put the phone away. “This is my time now.” … I knew that day that Michael was going to be gone by that night.’* (W465)

Respondents who felt that the person with intellectual disability had developed awareness often had a ‘feeling’ that this had occurred, rather than being able to say this with certainty:

> *‘Just from what I know of her really. I can’t pinpoint any particular thing, you know. Just looking back … And I would say she did, you know. Just my own thinking now really. Maybe somebody else might feel differently but I would say she did, you know. I have a feeling that she did.’* (W476)

Despite this, communication practices most commonly appeared to be closed in nature: *‘Should we be telling the person that you're dying? I mean I don’t… we've never done that, actually’* (W509). A sense of lack of ability to judge whether or not the individual understood, or a lack of confidence in their own communication skills was associated with hesitance to engage in conversation. The question *‘How do you explain to them? ‘Cos you know they don’t understand like we understand’* (W701) was one without an easy answer.

Additionally, the personal emotional response of staff could contribute to a reluctance to speak openly, *‘Yeah, you know it’s coming but still at the same I think you’re in denial kind of thing. You don’t want it to happen, I suppose’* (W201).

Most commonly, staff were motivated by a desire to protect the person with intellectual disability and prevent harm:

> *‘A lot of the time we kind of wouldn’t, I suppose we wouldn’t express to Paul what was ahead because we didn’t want to worry him. We didn’t want him agitated every single day because we had such happy memories with him and happy days with him.’* (W699)

Families appeared to have similar practices, as reported by staff, *‘...Families would be like, “Oh they don’t need to know that”. Or “You know, don’t be saying that. You know, it’ll only upset* *them."'* (W254). Both were protective because they were concerned that the person would be frightened or unable to cope because of their limited cognitive ability:

> *'I suppose my only thing would be, you know, the... the whole business of questioning people about their end-of-life care or any older person, do you know? I often wonder is it...? Just about the ethics of that- it's frightening, it can be frightening, especially for people with an intellectual disability who don't understand it.'* (W654)

While it was mostly felt that protection was the best approach to take, on occasion respondents reported that individuals with intellectual disability were frightened of the unknown when experiencing deterioration and ill-health:

> *'And I remember saying to him "You've no reason to complain of pain, you've no reason to fear." And he was gone, literally gone like that. Up to that, he was so… you knew by him, he was so scared. He knew there was something wrong and he knew he was in pain, and he didn't know what was going on. But it seemed that whatever…. Obviously, he must've known himself in the end.'* (W025)

Occasions where ID staff appeared more likely to engage in open conversation were associated with instances where level of disability was mild, hospital-based staff had initially broken the bad news, or when the person with intellectual disability demonstrated a desire to speak of illness. In such circumstances, staff ensured that reasonable adjustments were made to the provision of information: *'And we certainly made sure she had the information at her level. And at the pace she could, she could take it'* (W750). On one occasion the local priest who knew the individual well was reported as talking to a resident '*about what could happen'* (W270).

End-of-life decision making needs

Staff demonstrated awareness and agreement with the principles and ethos of United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) [6]. On a daily basis, they showed respect for the autonomy of the person with intellectual disability and a desire to respect the will and preferences of the individual to the greatest degree possible, including those with profound impairments and limited or no communication:

> *'… She couldn't communicate, no. But there were certain things that she didn't like done. So, those things weren't done if you get what I mean. You know, such things as she wouldn't like, yeah, that we would've known.'* (W713)

Support provided for day-to-day decisions was evident and included preferences about what activities to pursue, what to eat and who to spend time with: '*We all respected her wishes, even if we didn't agree with her getting up, if she wanted to get up, we still got her up … because it was important to her'* (W430). Staff utilised a variety of strategies to support decision making, including use of visual aids, careful timing of conversations, attention to non-verbal cues, facial expressions, gestures and mood and tailoring communication style to the needs of the individual. The following excerpt illustrates an approach where open questioning is avoided because of difficulties that the individual experienced in managing choice: '*They'd have nearly said "Now, George, this is what we're doing. But what do you think?" … They say, "We're doing it, but what do you think?"'* (W701)

This approach was continued in practice regarding place of care at end-of-life. Participant preferences on place of care were commonly sought:

> *'So, it was very much her own choice to actually stay where she was…. And her family then as well said "Well, the fact that she… that's her choice." We had to respect that'* (W114).

Preferences regarding place of care tended to be observed as far as was possible, even if it was difficult to achieve:

> *'…To be able to support him here in his house wasn't what normally would have been done. But his own wishes was so clear that we didn't, we couldn't sent him anywhere, he was so clear he wanted to stay here'* (W119).

Another ID staff member recounted how a person with intellectual disability did not settle following transfer to hospice*, '… He refused to go to bed for them and just he was… That was his way of telling them "I do not want to be here [in the hospice*]" (W465). This led to revision of the care plan, and the individual returned to their usual home environment.

Although significant weight was placed on eliciting or understanding preferences regarding place of care, people with intellectual disability appeared to be less well supported to engage in other areas of end-of-life decision-making. The difficulties involved in engaging with people with intellectual disabilities were noted:

> *'I felt I personally was the person who made the decisions around you know whether he should be doing radium treatment. And you know, I think maybe we could have included him a bit more… but how to do that? … You just feel afterwards… you think "Oh God, we*

> *could have done something more." Maybe, given… maybe gone into pictures a bit more or whatever. It's hard to know'* (W035).

Death and dying were often regarded as taboo topics and it appeared that staff more often defaulted to use of 'best interpretation of will and preferences' or 'best interests' when considering these topics, rather than more directly engaging with the individual with disability. This was in contrast to the approach taken when considering place of care, and it could happen even in situations where a person with intellectual disability had previously been involved in decision-making. For example, an ID staff member described an individual as having a *'… moderate learning disability. So, she wouldn't probably have had the understanding of it [her own approaching death]'* (W725) despite the fact that the individual had previously been supported to make a will.

In these situations, decision-making was commonly made in multi-disciplinary meetings that involved family members, but not the person with intellectual disability. Nonetheless, ID staff regarded this process of decision-making favourably. They felt there was benefit in the time and consideration given to the matter at hand, the involvement of different voices and perspectives, teamworking and the clarity of plan that usually resulted. Decisions remained 'difficult' as a participant explained, but the process was worthwhile:

> *'It's very difficult. We've had to [make an end-of-life care decision] a few times now, but I think generally, overall, the process is quite good. That everybody's there and it's a kind of a joint agreement with the family as well. And in a lot of ways, it puts people at ease then'* (W114)

On occasion, differences in opinion could arise. In such situations, considerable effort was usually expended to achieve resolution and communication was generally felt to be key:

> *'… In our experience, when somebody- when they're well and there's a discrepancy between what the doctor wants to do and what the person wants- really, that's a communication thing. We just spend time with the communication, you know. And that resolves itself.'* (W075)

Situations involving differences of opinion with family members were somewhat different, however. While similar time and effort was invested by ID staff in the process of communication, family members generally had significant influence, and this meant that their preferences generally held sway:

> *'Do you know maybe it's kind of a family decision? It's been discussed between the staff I suppose, and family kind of, but it's really the family who decide what is going to happen in the end'* (W201)

Even in situations without conflict, it was noted that the process of collaborative decision-making was onerous and resource intensive:

> *'It's a huge challenge to get this documentation completed. Especially now for HIQA and stuff like that. It's a huge challenge for us to get to that stage. Or to have everything in place, like. Because you know, trying to organise meetings is one thing, and then trying to bring these topics up in another thing'* (W254)

Pre-existing care needs relating to the presence of disability

It was noted that needs associated with physical or sensory disability remain when a life-limiting condition is diagnosed and should not be neglected. Moreover, ID staff noted that diagnostic overshadowing can occur where staff from mainstream services attributed signs of physical illness to the person's underlying disability:

> *'… I think just with the Down syndrome, they just fall into a bracket. And a lot of the time we'd kind of find, or I suppose the residents would find that they'd come up against the "Sure, look this is all part of it" kind of thing.* (W377)

Almost insurmountable problems were faced when people with an intellectual disability were unable to engage with or tolerate interventions focused on comfort. Fortunately, this did not appear to happen very commonly but when it did, it had significant impact, *'So yeah, he suffered more than he should have. But it was non-compliance on his part, rather than you know, it was offered there'* (W035). In such situations staff made significant efforts to address the problems- *'everybody, they would have gone out of their way'*- but the struggle in balancing autonomy against best interests was real (see section on 'End-of-life decision making needs', above)

4.2.2 The needs of peers

Relationships between people with an intellectual disability who lived together were usually long-established and often close. While some relationships were classed as friendships, others were characterised as being like family. A staff member explained the close relationship between one decedent and others living in a community home as *'...She was like a mother in the house, she'd be nearly kind of mothering the other ladies'* (W779). However, a spectrum of relationships was evident and for some, although they knew the individual with life-limiting illness, '*they wouldn't have had a relationship'* (W424).

There was acknowledgment of the impact of illness and bereavement on peers. Peers often needed support to understand or adjust to changes in behaviour from the person who was unwell, *'… they did most things in common and then because of pain, now she just wasn't interested. And we had to explain to them*' (W082). Living arrangements could be disrupted and peers could be asked to move bedrooms to accommodate the changing needs of the person who was unwell. Increased care needs could mean that less time was available for peers causing staff to feel guilty and stressed. The atmosphere in the house was felt to change in the days before death and staff commented that *'people pick up on it you know, they really do pick up on it'*, often becoming more *'sombre'* (W114).

Further needs were identified when peers became worried or concerned about their own health and end-of-life: '*So, I think they're a little but kind of nervous, or maybe they're worried themselves that they could be next, you know'* (W007). Fear could develop to the degree that bedrooms or places became associated with the dying person, and peers would worry that they would be affected if they entered those spaces:

> *'Because there were people who came here, and they were afraid to open the door. 'Cos they were afraid that if they came in here, they weren't going back out, you know. So, that's frightening'* (W701).

It was noted that even individuals who demonstrated little initial outward evidence of grief became distressed as the permanence of loss became apparent:

> *'But the effect was huge, even though we did bring, Mags, we call her, we did bring her to the funeral, and we did bring her to everything…. Like she didn't seem aware of it then, but then like there was no sleep for about two weeks.'* (W424)

The impact of loss and grief was felt by individuals regardless of severity of disability and could persist over time:

> *'Most of our service users are severe… they wouldn't have any communication skills that they'd be able to tell you like, but I do know one or two of them would still – actually, one in particular – would still call her name in the mornings… Like even still to this day, like.'* (W110)

Despite evidence of need, the degree to which support was provided to peers varied considerably. At one end of the spectrum, no formal supports to cope with grief or loss were available to peers: '*They did not receive anything, no'* (W025). Most commonly, it appeared that the regular staff members were the ones that were expected to provide supports:

> *'We felt that everything was being put on the direct staff member, whether it be health care assistant, social care worker or nurse, because we would have nurses here in this house as well. And I felt that what, what we were actually looking for was that maybe a counsellor, a psychologist, someone would come in who is specialised, who's dealing with this, and understands what questions to ask…'* (W119)

Services that had better resourced multidisciplinary teams offered advantage in terms of supports available, particularly when team members had acquired additional training focused on bereavement support. Such individuals were able to provide direct support to peers and also help other members of the team provide support:

> *'One of our social workers is a trained counsellor … And she does bereavement counselling … And we would have been told as well how to manage it and that- like let them freely chat about it, obviously it'd be different that the normal grieving process.'* (W030)

Pastoral care also often provided support to peers, engaging them in conversation, prayer, and services of remembrance. Staff members who had worked in settings where a proactive approach to support was taken could see the benefits of this. A staff member remarked on their changed approach:

> *'I think it will probably be at the forefront of my mind now that definitely we're going to debrief and that. And definitely we're going to have a counsellor come down and make him or herself available instead of us just saying, "Look, if you want to talk to somebody, we can contact somebody."'* (W377)

In contrast, a staff member who was working in an environment which lacked multidisciplinary input commented:

> *'It wasn't very supportive, but it was alright you know. We just… you know, you just have to get on with life. There are other things going on, so I think it affected different people in different ways. So, we tried to support each other, and the service users too, and that was…. You know, you just get used to it.'* (W015)

ID staff commented that peers generally benefitted from opportunity to be physically present and to experience events first-hand in a supported environment. They felt that this helped people with intellectual disability to understand what was happening and to process feelings of loss or grief. For example, a participant explained:

> *'I remember taking Gerry in to see the open coffin. And he'd have- Gerry was an older man and Gerry would've been lower level … So I wanted him to understand…. And he understood, you know, and he went over, and he touched him [the deceased] and he spoke to him.'* (W457)

Overall, changes in culture and approach to the provision of support to peers was observed to have happened over time. A participant summed it up as:

> *'I think in the years that I … have been here, being open about it and taling about it … has done so much you know. That it's open and we talk and talk about the person has made such a big impact. Compared to what we had to do when … I was here first.'* (W750)

4.2.3 Emotional and psychosocial needs of family

Like the general population, the impact of a life-limiting illness extends to family members. Given that most decedents lived in community or residential care settings, staff were aware of the effect on families, and they endeavoured to provide support where they could, *'Talking to the families and... do you know that kind of way? Do you know? I suppose, being there for them.'* (W204). It was noted that the experience of receiving or providing support could be affected by the quality or nature of relationships that were formed between ID staff and families:

> *'His family… they think we supported them brilliantly, but I think they supported us fantastically too … it depends on the relationships you have, how people are… it's not that you're trying to make much more of some people and less of others'* (W509)

Generally, the intensity of input from family members increased towards the end-of-life:

> *But yeah, definitely in the last six months, then her family were visiting her all the time. And there was one of her sisters in particular, Kate, she was here a lot, in the last three months. And then the last couple of weeks, we were in real good contact with them you know.* (W207)

For some families, a lengthy illness could mean that this intensity had to be maintained over a long period, and a sense of responsibility could lead to families being in a state of constant awareness of the possibility of further deterioration: *'Cos, he said himself, he was very reluctant for the last year or more to go on holiday. You know because he was saying that he was always waiting for the call' (W254).* As with the general population, strain associated with illness could heighten other pre-existing issues: *'So, they did everything that they could possibly do, and they were all elderly …despite their own feuds! Because there was all those dynamics going on, as well'* (W739).

In residential or group home settings, families could develop close relationships with the peers of their family member and become involved in supporting those individuals also: *'So, it was the family who were helping the residents because they were very attached to the other residents, you know' (W408).* Other families, however, had maintained a more distant presence, and were largely unfamiliar with the life that the person with disability had been living or the relationships that the person had with their peers until the terminal phase of illness and death:

> *'And the family realised when, when she was brought back [to be waked[10] in the community home], and they were there in the sitting room, and the clients were in and out, and they realised how much they [the residents] liked her [the deceased]'* (W583).

Staff were appreciative of the times where family members respected the important place that peers had played in the life of individual with intellectual disability and when the needs of peers were considered by the family:

> *'Thank goodness, they left her in the house, they waked her in the house. Everybody that had known her all the years from here could go down and wander in and out, and the family kind of just sat… It must have been hard for them as well when you think about it, because if they know this is happening and yet they don't have full control…'* (W779)

For those family members who had maintained close relationships with their family member with intellectual disability following residential care placement, it was acknowledged that a large part of 'normal life' was lost for the family member in bereavement:

> *'Because they've been involved in the service the length of time that Mary has been here. Do you know, between getting letters or phone calls or coming in visiting. Meeting staff,*

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[10] A wake is a gathering held before the funeral (usually in the home of the decedent) where family and friends keep a continuous vigil for the decedent.

> *meeting the other ladies, like you know. Like- and it is, it's like another little thing for them. And then when all that… when the person passes away, all of that is cut off…'* (W207).

Chaplaincy could play an important role in supporting families at time of loss:

> *'…then they might say the rosary and things afterwards and stiff. Like they're very much involved too in the funeral and that side of things afterwards. Talking to the families …. I suppose being there for them …'* (W201)

Bereaved family members sometimes wanted to maintain a level of contact with the ID service after the death of the person with intellectual disability, and this could be of help in their grieving. As a family member explained:

> *'… And I met them [the ID staff]. And we had tea, and what have you. And we chatted and we talked. And actually, I found it very therapeutic for myself.'* (W779)

4.2.4 Emotional and psychosocial needs of staff

Although staff were professional caregivers, they had often established long and close relationships with decedents. Sometimes, staff were the people with whom the person with intellectual disability had the closest relationship:

> *'Like he was here since a very young age, about one or so. Came directly from, like I suppose what you would call a mother and baby home and had no known natural family as such, so the paid staff members here would've been the closest thing that Liam had ever known to family.'* (W117)

This meant that staff were understandably affected when a resident became unwell and there was a strong desire to provide care for the person to the best of their ability for as long as possible, *"The staff did not want to let her go. But it was just... I think we take it real personal ourselves, and hold on to people as long as we can, you know?"* (W201). Situations where a resident

Situations where staff doubted their capability, or the quality of care provided to the person with intellectual disability appeared to have long-lasting impact:

> *'I suppose that's something that would play on a lot of the staff here. That you know, he would've been in pain. But he didn't, you know he couldn't, you know his words were so limited. That he really, you know couldn't communicate. And we found it very difficult to communicate with him.'* (W377)

As with the general population, being closely involved in witnessing an individual's decline can be accompanied by feelings of profound sadness or helplessness: *'We wouldn't force her to do anything, like you now, which was heart-breaking when she wouldn't eat or drink, like'* (W264). The sadness that staff experienced because of the illness of the person with intellectual disability could be compounded by staff shortages, and the responsibility of meeting both the needs of the unwell resident and other service users. A sense of lack of competency and need to care for the ongoing needs of other residents added further strain:

> *'No, I wouldn't say no I wouldn't say we got great support. I suppose from the staff ourselves we all supported each other very well. And you know supported the clients as much, our residents as much as we could…. I know one of the staff still feels that she wasn't, you know, that she…. cos it was an area that she wasn't at all familiar with. And she still, says she still would think of it. And she still... like that, she said for a long time, you know, when she was on nights, she'd be down the hall bawling crying inside in his bedroom.'* (W268)

Conversely, effective teamworking, fulfilment of the wishes of the person with intellectual disabilities and the achievement of a good death afforded staff with a sense of achievement:

> *'So, I think everyone in the service really wanted to give him like a peaceful, a comfortable death, with his own wishes which was to stay here. So, there was a great sense, you know, that we really supported him right until the end…. So, I do think, it was a great experience…'* (W119).

The supports available to staff to help with emotional distress at these times varied. Staff generally did not appear to utilise Employee Assistance Programmes or formally designated points of contact within services such as GPs. Instead, most favoured approaches involving collegial support- *'if someone's having a bad day … go and have a cup of tea there like and think, do you know, sit down and relax a minute'* (W201) or team debriefs. A number of respondents noted that team debriefs were changing from ad hoc arrangements to more structured processes of after-death reviews and this was regarded favourably by those respondents who had experience of it:

> *'… well, it's a structured approach to it now. So it goes on for I think a month afterwards. You meet every week and the staff come in and they chat about it … So it could be the bus drivers, they can come in and sit in on it and chat about it… 'cos they'd have a good relationship with service users as well … It's great … '* (W114)

The value of managers, pastoral care, or social workers increasing their contact and follow-up with staff and engaging with them in a more organic way by calling in or visiting regularly in the weeks following death to check in on staff was also noted:

'Because sometimes- especially you know around, you know, eating and drinking, sometimes staff might feel, are a bit kind of thinking *"Jesus, did we do the right thing?"… So, we just kind of recap on them bits [the positive aspects of care provision] just to leave it on a kind of positive note.'* (W054)

4.2.5 Place of care and care transitions

Place of care was a complicated and emotive issue. Staff placed a high value on maintaining familiar environments and familiar relationships for the person with an intellectual disability and wanted to provide end-of-life care in the home environment whenever they could. All decedents had spent at least some time in their usual home in the last three months of life, and staff expressed satisfaction when a service user died in their own home. It was clear that it was important to many staff to accompany the person with an intellectual disability through the final stages of their life, and a sense of achievement was evident when a person was enabled to '…*end her journey in her own home and in her own bed*'.

Interviewees explained that people with an intellectual disability experience any change as stressful, and they therefore were reluctant to make any changes to place of care unless absolutely necessary. Even a move from one part of an organisation to another was regarded as disruptive. A staff member explained that "*Yes, moving clients here is something. They really... you know…. it affects even their physical conditions'* (W220). Moves outside the organisation were often felt to be particularly traumatic:

> *'And then he just kind of gave up I think in the end. And to me and to a lot of us that had worked with him, we could see the change in Brian after he left [name of organisation], where he'd lived for so long. He slowly went downhill; I'd say he'd a broken heart as well at the back of it all, but it was pneumonia initially that he went into hospital with.'* (W205)

Effective provision of end-of-life care required an appropriate and supportive environment, and there was acknowledgment that shared accommodation spaces were outdated and that *'from a privacy and dignity [perspective] ... I definitely wouldn't say it was conducive [to best practice care]*' (W114). Additional equipment was often needed: *'… We got everything that was required- like her slings, and her chair, and we had her own room'* (W110). The general trend around improving accommodation within organisations providing residential care was felt to be essential to sustainability of care provision in the longer term.

Adequate numbers of appropriately trained and willing staff were essential, and challenges were encountered by organisations who primarily provided a social model of care:

> *'And this is a huge thing that has come into play …. Because we've a lot of people recently diagnosed with dementia. And diagnosed maybe two or three years of dementia. And it's because we're not medical, we have to look at… We would have loved to have kept Brian in the house. But you see, he wouldn't needed a whole medical need'* (W030).

Increased numbers of staff were often required, and as a respondent commented, sometimes this required the use of agency staff: *'…That's what we had to do in the end, like, would have been a one -to-one [staffing ratio] with her … we had an agency staff'* (W110). Funding for additional staffing did not appear to be in constant supply:

> *'There was someone with him all the time from the service. If it were now, I really don't think that would happen. I mean things like staffing seem so different now since January- I don't know if we could've done it'* (W117).

it was also important that the staff were of the right skill-mix to be able to provide care. A respondent explained, '*Strongly agree [that there was enough help with nursing care] but the issue was, like, I suppose just giving medicine and all that'* (W035). Partnership with the SPC team was viewed as an enabler to supporting care in the home environment:

> *'It was discussed, hospice care or to be cared for here, in her own home, with support from the community palliative care team. So, that's what the plan was, and that's what happened with no readmission to hospital again'* (W254).

Even when staffing and training were provided, for some organisations, there remained limits on what could be provided: *'If she'd have been on, like we'll say a morphine pump or anything like that … we probably wouldn't have been able to provide that- the decision would have been taken out of our hands'* (W110).

Timely and clear decision-making around goals of care allowed staff to engage in the necessary planning to support care, and effective team-working helped this process:

> *'We were then able to call a meeting and say "Right"- looking at staffing, looking at training, he was to get subcut[aneous] medications, how we were going to upskill all the staff, how we were going to train all the staff? And it was really from the kind of collaboration within the service'* (W119)

Despite the success that services experienced in facilitating end-of-life care in the home setting, for many services there remained a sense that this was often achieved against the odds, rather than being a reliable part of the ways services were organised. This was captured in the following excerpt:

> *'You had a group of people who were working with Leona who decided they were going to make this happen for her, who listened and made it happen. You had a family you were equally, you know, determined to make It happen as well, and put in huge resources themselves. You had a HSE funder who said "Go for it- because this is the wishes of the person- so go for it, and we'll sort out the details afterwards". And you had a clinical team that supported Leona, who just- she seemed to garner people to be at the top of their game, all of the time.'* (W750)

Hospitalisation

Respondents painted a mixed, although generally favourable, picture of care provided in hospitals to people with an intellectual disability. It was commented that *'They've improved hugely for people with an intellectual disability in the acute sector'* (W440) although it was almost universally felt that the person still benefited from having a family member or ID staff member present to advocate for them and assist in personal care provision:

> '*Whenever she was in hospital, the care was good, and we gave support from here as well. We always had staff over there to give them support because they wouldn't know her' (W082).*

The importance of familiarity and knowing the person with an intellectual disability was again stressed: '*Just to be…. for her to have a familiar voice. Because I mean in the big hospital like they wouldn't know her'* (W476). Staff felt worried and guilty when staff could not be provided to sit with the person with an intellectual disability in the hospital. This was an increasing problem due to resource constraints. A participant explained *'You're told, "Well we haven't the money to have someone going in there [to the hospital]." It always crops up'* (W030). Hospital environments, by their nature, were felt to be busy and short-staffed environments where older people and people with mental health problems were also vulnerable.

Respondents valued times when there had been sensitive and skilled communication, kindness shown and when accommodations had been made to the needs of the person with an intellectual disability such as affording the person additional time or making sure that the person didn't wait too long to be seen. The importance of team-working between hospital and ID staff was emphasised, as exemplified by the value that ID staff could bring in helping hospital staff tailor their care to the needs of the individual: *'So that was one of the things that we worked closely with the hospital with them. That we, you know, recognise that her recognition of pain was different from other people's'* (W750).

Experience of care was variable however, and several instances were spoken of where respondents felt that poor quality care was given. In some instances, staff reported that the basic care needs of the person with an intellectual disability had not been met since it was overlooked or not recognised that additional assistance was needed. On other occasions, ID staff weren't listened to, meaning that distress wasn't recognised and/or behavioural disturbance escalated. Link people within the hospital who had trained in intellectual disability were felt to be a useful resource *'it's been very, very good'* (W030) but that model was localised rather than widespread.

Care transitions- to move or not to move?

Given that staff felt that people with an intellectual disability experienced emotional and physical ill-effects from a change in living environments, even when it was not possible to continue caring for a person in their home environment, staff tried to delay the move for as long as they could. This commitment often took a toll on the members of staff providing care as illustrated, *'And we were kind of getting to a stage, night staff were getting up four or five times a night. Or the sleep-over [staff member] was getting up. And they weren't telling anybody. 'Cos, they didn't want her to move out of the house'* (W201).

Despite reluctance to move service users, staff did acknowledge sometimes there was no other feasible option. Staff were particularly aware that the care of other residents could be impacted by the increased needs of one individual, such as an instance when '*their privacy and dignity was being hampered by John's decline'* (W346). From past experiences, there were times where staff felt that the needs of the individual could be better met elsewhere:

> *'I'm looking at Mary [who has advanced Alzheimer's dementia]; now I know it's nice to keep her in her own environment. Because it's like if anything happened to your mammy*

> *or whatever you'd like to keep them in their own home, right? But my personal thing with Mary now- where she is in the community house, I feel she needs more care, and she needs the professionals, and she needs a nurse.'* (W457)

It was noted that the challenge of sustaining care at home for a person with advanced illness is something that is not unique to people with an intellectual disability:

> *'So, for any of us, when we get to a stage where we're not able to continue to live in our home, we may have to end up in a nursing home. And I suppose it's probably no different for our service users.'* (W725)

Experience of transitions of care:

Although staff were sad to see the person with intellectual disability moving home, in most cases it appeared that the move had been managed well. The quality of care that was provided in the new location acted as a reassurance to staff that the decision to move had been the right one, such as in the case of a respondent commenting on the care received in a nursing home as being '*excellent, excellent'* (W442). When a service user moved within an organisation, a staff member often moved with the individual to ensure continuity of relationships. As a staff member explained, '*Staff that would have known her would have moved with her then to support that kind of transition for her then as well'* (W080). When transitions were supported in this way, it appeared to act as a powerful reassurance that the right decision had been made and it eased the transition of care.

In a minority of cases, however, the move was felt to be detrimental to the person with an intellectual disability. Staff described the ways in which they felt the wrong decision had been made, commenting *'But you know, [it was] just a massive failure of...kind of... continuity, or value of the home environment, or, you know, person-centred care, you know*?' (W377). A lack of involvement appeared to be a risk factor for poor outcomes- a staff member commented on their experience as '*We had no decision in where he was being moved to, we were just told. And his family had very little say in where he was being moved to also. And we were told that when he got his bed, he was going to a dementia-specific unit. And it wasn't, it definitely wasn't' (W025).*

Staff and families were distressed by these experiences which remained fresh in their memories:

> *'And then he just kind of gave up, I think, in the end. And to me, and to a lot of us that had worked with him, we could see the change in Jim after he leaving the Lodge, where he'd lived for so long. He slowly went downhill; I'd say he'd a broken heart as well at the back*

> *of it all, but it was pneumonia initially that he went into hospital with.'* (W025)

Of note, it appeared the risk of disenfranchised grief was even higher in situations where a resident was moved out of a service to a nursing home or other location where they subsequently died because bereavement or employee assistance supports were not usually provided. As a participant explained:

> *'It's not available … because he had moved out from us, there's nothing there to support staff. Because he was gone from the service.'* (W025)

4.2.6 Place of death

As previously noted, respondents generally regarded home as the preferred place of care for people with intellectual disability and home was also regarded as preferred place of death. Hospital as place of death elicited more polarised viewpoints- some felt that it was the 'right' place, but others regarded it as a failure in care. Respondents who reported that hospital was the right place to die were generally of the opinion that the person with an intellectual disability had deteriorated relatively quickly and that the hospital had provided something in terms of medical treatment that the ID service could not offer. In such situations, the perceived best interests of the individual appeared to bear strong influence, and there were not felt to be alternative options. As a participant explained: *'It was the only option… She required IV fluids and everything, you know, so she needed to go'* (W517).

Respondents who reported that the hospital was the wrong place to die variously reported that the person with an intellectual disability was frightened or lonely outside of their familiar environment, or that a plan had been in place to keep the person at home but that unexpected events had prevented that plan being executed.

Respondents generally indicated high satisfaction with hospice services, including as a place of death. Even so, the importance of listening to the person with disability's voice and personal preference was evident when one ID staff member spoke of one individual who had been admitted to the hospice but just did not settle there- '*So, he refused to go to bed for them and just he was… That was his way of telling them "I do not want to be here [in the hospice]"* (W465). As a result, the individual returned home and was supported to die in their preferred place of care with the support of the community palliative care team.

4.2.7 Palliative care provision

Demographic changes provided the impetus for services to upskill and develop their own abilities to provide general palliative care. Services were at varying stages of development; some services noted that this was '*new area of service delivery for us'* while others had developed confidence in their capabilities:

> '*It's just that we have a very good grasp here of end-of-life. We specialise very much in it, because a lot of our residents, you know, are that age. And we're well experienced really now in this area. And you know it's an amazing thing, when we come into work on a morning and if somebody is, if we realise they're at end-of-life, automatically we know what to pick up and who to ring and what to do.' (W713).*

The change over time was evident to ID staff who commented on the advances that had been made:

> *'Cos a lot of us would have been through the process before. And I suppose in the last maybe ten years, there's been, there's a lot more research and education in relation to it. And in relation to pain, you know, so, yeah, I would have been confident that, you know, we were… competent is the word I'd use, yeah, in relation to her pain.'* (W114)

However, despite developing capability to provide general palliative care, commonly ID services appeared to default towards involvement of SPC services in care provision regardless of capability or level of need:

> *'See I'm palliative care trained, I've a Masters [degree] in palliative care and all the nurses in [name of organisation] did a six-week course in palliative care. But we still involve the palliative care team when it comes towards end-of-life.'* (W430)

The involvement of SPC services appeared to offer a level of reassurance that staff valued, even when they acknowledged they were competent to provide care themselves:

> *'His decline all happened very quickly, so I just felt that … if the MDT meeting, just say, was held sooner, the referral would have went in sooner, and perhaps the palliative care team would have come out sooner, before he passed away. However, the palliative care team wouldn't have done anything different to what we done, so he still got the care.'* (W119)

ID services reported that working relationships were *'excellent'* and communication was generally felt to be *'brilliant'.* However, it was clear that ID services most often adopted an approach where they deferred to SPC and followed the lead of SPC staff in decision-making. It was explained that '*It's kind of really their decision. But you, kind of I suppose advocate for the person that you're minding'* (W201). Reflecting on their organisation's experience with SPC, one respondent offered a differing perspective, remarking that '*I think we could've taken a stronger lead. Instead of... kind of at the time, we were sort of waiting to be told by the palliative care team what we could do. And I think we could have… we could've taken the lead. And told them what we needed to do, what we needed from them'* (W750). The respondent went on to explain that they were now more assertive in their engagement with SPC.

Specialist palliative care provision

Respondents held the SPC services in high regard, *'Oh yeah, I mean you couldn't [say] highly enough how great the service is' (W465).* Respondents valued the support and expertise of the SPC team in ensuring that the person with an intellectual disability was able to die at home. It was felt that services shared a similar ethos of *'dignity and respect'* (W408) and that palliative care had a *'very good understanding of ID'* (W384). Once the SPC teams were involved, it noted that they were easily accessible, and it was often remarked how frequently SPC teams would visit towards the end-of-life. Their helpfulness and approachability were highly appreciated - as respondents remarked '... *no question was silly'* (W465) and '...*we could ring them any time.*' (W779)

Specialist palliative care teams were most often only involved in care in the last days or weeks of life. It was clear that palliative care was still strongly associated with end-of-life care, and that *'Like for his death and dying, he would've dealt with the community palliative care nurse'* (W016). At the end-of-life, the input of the SPC team appeared to be most sought for assistance with pain management and the use of continuous subcutaneous infusions. It was seen as the role of the team to *'put in the, you know, the pumps and all that sort of stuff'* (W007). Contributions to care planning and coordination, communication with families and education of ID staff were also noted, but the dominant theme was that of assistance with provision of care focused on the end-of-life.

Although SPC was most often involved towards the end-of-life, there were some instances where referrals were made earlier. When SPC teams were involved earlier, their input varied according to need, and usually increased in intensity as illness progressed:

> *'Initially it was around just the symptoms but once that was sorted then really there was... it might have just been a phone call maybe or something just to run something by her. But it was a very open kind of relationship like once if we were in any way anxious that something wasn't right, or we didn't feel she would have come. But I suppose in the last couple... probably daily... she would have been in with us daily, anyway.'* (W054)

One area of dissatisfaction was notable, however. There were several occasions where the ID team looked for early involvement of the CPC team but were told that *'that they don't do anything until such a time as there was no intervention taking place. In other words, if you're not on antibiotics, you're not feeding, you're not… that's the only time that the hospice comes in.'* (W491). ID staff were clearly disappointed in this approach because they felt they were unable to manage some refractory symptoms that occurred earlier in the course of illness. One respondent recounted their difficulty in responding to a service user's distress: '*Because she had been in a lot of pain and discomfort. No matter what you done.'* (W28)

Staff working in ID services also felt that there were times where earlier involvement of the SPC team would have helped with care planning; one respondent explained, '*And like that, it's not until she had become symptomatic that we'll actually get kind of information from them. Or get a person to come in and, like, tell us like the plan, you know.'* (W24). Finally, earlier involvement would allow relationships to build over time, which staff felt was essential for effective care to be provided to people with an intellectual disability because *'…they can't just get involved at the end because it's too difficult for everybody, because they don't know the person and the person doesn't know them.'*

4.2.8 Funerals, memories, and legacies

Funerals and remembrance services

Funerals and remembrance services played an important role in honouring, respecting, and marking life and death. All of the funeral services that had taken place were Christian, and the vast majority were of the Roman Catholic faith.

For those decedents who were living in residential care, if the decedent had family alive, then the closest relative ultimately had authority over funeral arrangements, regardless of whether or not there had previously been close contact. In most situations a collaborative process was adopted between family and ID staff in deciding arrangements. However, a spectrum of participation was observed. At one end of the spectrum, family led on the arrangements with ID staff playing a supporting role, at the other end of the spectrum ID staff took the lead role. As one ID staff member remarked for those instances when they took the lead:

> *'You'd have to organise everything down to driving the family to the shop to buy butter [for sandwiches for mourners] because they had none at home…'* (W440)

The organisation of the funeral service was a time-consuming and sometimes stressful task for ID staff members if they themselves were under-staffed. However, generally it was something that was felt to be important to do in memory of the person who had died and was of help to family:

> *'Oh, I remember the morning of the removal being inside in a meeting and my phone- I had my boss's phone, my CNM 2 at the time, and it never stopped ringing between the priest, the undertaker, the florist … But we had to do it then to support the family because I think they were in such shock that it had happened; they didn't want to be interfering because it was happening on site …'* (W424).

The personal attachment that ID staff often felt for residents was manifest in the 'extra mile' that staff went to in order to ensure that the person was treated with dignity and respect even after death:

> *'It varies with everybody. In that case, two of us went to the funeral home and helped prepare her. We did her make up and her clothes. Now, that's not… that's not written anywhere as part of our job … we volunteered to do it … And her- the other thing that happens here is that her regular hairdresser came and did her hair … And she does that voluntarily.'* (W654)

Respondents commented on the important role that mourning rituals played in helping peers understand the reality of death. If the decedent had lived in a group home setting prior to death, it was felt to be of particular help to wake the person in their own home. The other residents then had the benefit of being in a familiar, safe environment where they could 'come and go' when paying their respects and viewing the coffin:

> *'And the clients then came in and out, you know. And like it was amazing really, you know, to see other clients and they'd go over to her and "Ah, poor Mary", you know or "Mary is gone to heaven now", you know.'* (W583)

An individualised approach was taken to involvement of the other residents in the wake or funeral. A staff member explained how *'… all the clients were all asked did they mind if Kate [was waked in the house] and they said "no", they wanted Kate to stay in the house'* (W430). Another staff member explained how although they held the wake and a remembrance service in the group home, '*Mike, one of the residents here, he can't do any of that, so he sits inside in the activation room. And that's understandable, he's expressed [his wishes not to take part] and we respected that.'* (W699)

Most often, families appeared to recognise the role that the residential care setting or community house had played as the decedent's 'home' and arrangements were made accordingly:

> *'… Generally, because all of our clients have lived so long with us, the families usually want them- well, it's up to them whether they want them waked in the home or whether they want to take them outside or not.'* (W430)

In situations where the hometown of families was at a geographical distance from the ID organisation or on rare occasions where residents were felt to be less welcome to attend services, efforts were made to find ways of involving residents and marking the occasion:

> *'… we had a mass here for him, and then he went home to his family and they had you know waked him at home and they had their own mass in the church of [their local town].'* (W499)

Funeral services were characterised by personal attention to detail and involvement of the entire community:

> *'And then we usually do the church service and like their friends say things and say their little speech or friends will bring up the gifts and some of our service users are in the choir so all of that is very much involved … I did a little reading about Patricia from myself about her life and what she was like at the church and then another one of the girls sang her favourite song, one of the staff'.* (W622)

The legacy of institutionalisation was evident in the importance that staff placed on the way in which the final chapter in the decedent's life and death was managed. Care was taken to acknowledge the death of the individual and to inform and support other residents:

> *'Because we have, we would've had a lot of older people who … know each other for a really long time. And originally, what they tell us is that people would just go missing. They*

> *would just disappear from their room …. I mean no one ever told them what happened to them. So, we- I suppose in a sense- we celebrate a death. We announce it, we tell people very discretely individually or in little groups … we have prayers immediately, we say a rosary and we put a little, we put a picture of the person out on the front desk.'* (W750)

Public recognition and acknowledgement by the family of the individual's death was welcomed, even family members had not had close contact:

> *'But then when it came to it, they [the family] were very adamant that they wanted him – now they did let us kind of wake him here for a night - but they wanted him laid out in the funeral home in [their hometown]. And you know, there was none of that, like there was no kind of hiding it away … he was buried in the family plot … it was very open.'* (W440)

Although decisions to bury individuals close to the family home sometimes meant that this was distant from the ID organisation, there was a notable sense of closure and of putting things right that was associated with reuniting the person with intellectual disability with their family:

> *'We had a bit of travel with it [to the funeral] but I think it was kind of a nice decision to make … Ned wouldn't have contact with his parents a lot in his life. So, it was kind of nice, we all felt it was nice that he was buried back with his family.'* (W557)

However, when this was not possible, evidence of the ties and relationships that had developed over life between ID staff and those they had provided care to, and that persisted after death was made clear in the following excerpt:

> *'And what we tried to do was we tried to maybe locate [his mother's grave] … but it was full, her burial place ground was full. So, we said "okay", well you know we kind or decided then … he spent the last nine [years] here, good memories of his life here, so let's just bury him here …we just really wanted to keep Larry close, you know'* (W699)

Memories and legacies:

The month's mind was viewed by many as a particularly significant time period and many ID staff felt that it was important not to rush to fill the place of the deceased person who had been in receipt of services with another individual. Although staff acknowledged that there were pressures on organisations in terms of wait lists and persons with intellectual disability who needed services, it was felt that it was disrespectful to the decedent and counter-productive in terms of the grieving process. A staff member explained how *'it aways feels like you're replacing* *the person … Things tend to get upset if they tried to move anyone … 'til everybody settles … And people kind of come to terms with things.'* (W201)

For many, the memory of the person who had died lived on through story-telling, mementoes, annual services of remembrances or visits to the grave. Photos or personal items were often kept in group homes or spaces created in gardens or quiet places. Families sometimes maintained contact with the organisation, returning to visit or fund-raising for the care of other residents. While these actions were most often borne out of personal ties and relationships and were viewed as a natural part of honouring and grieving for the individual, it was remarked by some that the life of the person with intellectual disability had offered '*learning and legacy*' (W779) and that it was important to capture that in order to continue to improve the lives of others.

IDS-TILDA participants had lived through periods of immense change in the provision of ID services and more generally in society. They had experienced some of the lowest points of service provision to people with intellectual disabilities in the history of the State and through their participation and sharing of experiences, had helped to change the way care was provided. A family member explained how a staff member had spoken to her shortly before her relative with intellectual disability had died and had said how *'that as a result of her [the person with intellectual disability's] influence that you know it had influenced the way they had cared for people'* (W779). Another staff member relating the lessons that she had learned from those that she had cared for over the course of their lives but also the course of their deaths, summed up her feelings:

'So, I am humbled by it all. And also, as I said, hugely honoured to be a part of it. And also part of what we're doing now, which is helping people get out and have their lives. So, it's a great job'. (W750)

4.3 Changes over time

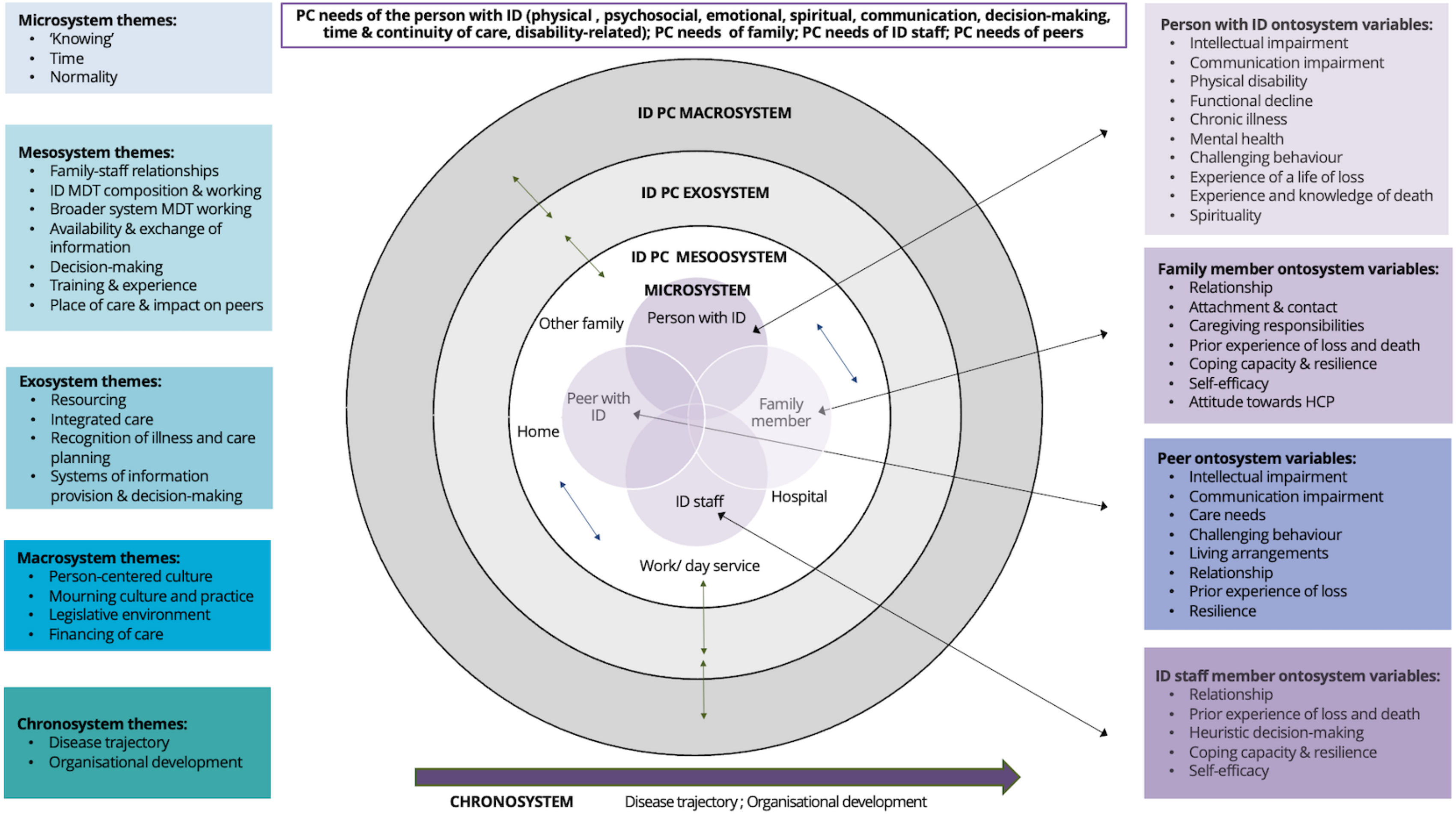
A sense of change over time was evident from the qualitative interviews. While the legacy of family separation and institutionally based care was still evident, newer models of care meant that service provision had moved towards individualised care in the home or community setting wherever possible. The will and preferences of the individual with intellectual disability were increasingly guiding care and multidisciplinary team members were working collaboratively with people with disability and their families to develop person-centred care plans focused on maximising independence and quality of life. Nonetheless, changing demographics meant that planning and meeting the palliative care needs of an ageing population was a topic of significant importance.

Respondents were acutely aware of this and placed high priority on ensuring that people with intellectual disability received comfort and dignity at the end of life. As a participant stated, *'The thing is, we want the best for them'* and that while it had been a '*learning curve',* things were often felt to improving (W030). When respondents did feel that care was better, this was because improved processes were noted to be in place, such as multidisciplinary and advance care planning, adequate staffing, engagement with specialist palliative care services and reflective practice, including after death reviews. Often staff felt that they were knowledgeable about the provision of end-of-life care, and that training had been of benefit. However, some staff did not feel as optimistic, and indeed it was stated without prevarication that '*Things have not improved … I've never heard management say, or discuss you know, "Oh maybe if something like that happened again, we'd, you know, we'd look into doing this differently"'* (W377).

4.4 Further development of the ID PC ecosystem

Data analysis corroborated and strengthened the conceptual model of the ID PC ecosystem as illustrated in the preceding sections of this chapter and as discussed in Chapter 5. Of note and as evidenced by the findings presented in this chapter, four additional topic areas emerged from analysis that had not been adequately considered in the first iteration of the ID PC ecosystem model. These were: spirituality as an ontosystem variable of importance to people with intellectual disability; heuristic decision-making as an ontosystem variable affecting intellectual disability staff; recognition of illness and care planning as an exosystem theme; mourning culture and practice as a macrosystem theme. This led in the development of a second iteration of the model, presented in Figure 5.

Figure 5 Intellectual Disability Palliative Care Ecosystem v2 [11]



Microsystem themes:
- 'Knowing'
- Time
- Normality

Mesosystem themes:
- Family-staff relationships
- ID MDT composition & working
- Broader system MDT working
- Availability & exchange of information
- Decision-making
- Training & experience
- Place of care & impact on peers

Exosystem themes:
- Resourcing
- Integrated care
- Recognition of illness and care planning
- Systems of information provision & decision-making

Macrosystem themes:
- Person-centered culture
- Mourning culture and practice
- Legislative environment
- Financing of care

Chronosystem themes:
- Disease trajectory
- Organisational development

PC needs of the person with ID (physical , psychosocial, emotional, spiritual, communication, decision-making, time & continuity of care, disability-related); PC needs of family; PC needs of ID staff; PC needs of peers

Person with ID ontosystem variables:
- Intellectual impairment
- Communication impairment
- Physical disability
- Functional decline
- Chronic illness
- Mental health
- Challenging behaviour
- Experience of a life of loss
- Experience and knowledge of death
- Spirituality

Family member ontosystem variables:
- Relationship
- Attachment & contact
- Caregiving responsibilities
- Prior experience of loss and death
- Coping capacity & resilience
- Self-efficacy
- Attitude towards HCP

Peer ontosystem variables:
- Intellectual impairment
- Communication impairment
- Care needs
- Challenging behaviour
- Living arrangements
- Relationship
- Prior experience of loss
- Resilience

ID staff member ontosystem variables:
- Relationship
- Prior experience of loss and death
- Heuristic decision-making
- Coping capacity & resilience
- Self-efficacy

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[11] ID: intellectual disability; PC: palliative care

Chapter 5. Discussion

5.1 Premature mortality

This dissertation reports on a representative sample of decedents from IDS-TILDA, providing a population-based overview of end-of-life care provided to older people (>40years) with an intellectual disability in Ireland. It has long been known that nationally, and internationally, people with an intellectual disability have a limited life expectancy in comparison to the general population- the finding that by the end of wave 2 data collection, 14.2% (n = 107) of IDS-TILDA participants had died with a mean age of 62.83 years (45-86; SD 11.0), is in keeping with that trend. Methodological challenges make study comparisons difficult- for example, TILDA recruits participants aged 50 years and over, but it is notable that TILDA reported only 6% confirmed deaths between Wave 1-Wave 3 data collection and that the mean age of 77.7 years. The difference between the two populations is significant- IDS-TILDA decedents were more likely to have died by Wave 3 data collection than TILDA decedents, X2 (1, N = 9257) = 73.06, p < .01. These findings are in keeping with a systematic review that found that the average age of death for people with an intellectual disability died was up to 20 years earlier than the general population. [180] Despite improvements in longevity for both in recent decades, the gap between the two populations has not narrowed. [39]

A recent Irish study using data from the National Intellectual Disability Database confirmed that adults most at risk of dying young are persons with more severe and profound disabilities and those who live in congregated residential settings. [40] The findings from the IDS-TILDA End-of-Life Study support this- nearly three-quarters (71%; n = 76) lived in residential care settings, and only 8.4% (n = 9) of decedents had mild levels of intellectual disability. The fact that such a high proportion of decedents lived in residential care settings is reflective of Ireland's historical legacy of providing care in 'congregated settings', i.e., institutions with 10 or more residents. Concerns about standards of care, and growing realisation of the fact that people with an intellectual disability have the right to live independently in a place of their own choosing has led to policy change. [181, 182] Nevertheless, despite evidence of benefit, re-location has been slow. [183]

These data reinforce the fact that people with an intellectual disability continue to experience premature mortality and point to the importance of advancing knowledge of the factors directly and indirectly contributing to shortened life expectancy, as well as understanding factors that influence quality of care at the end-of-life. Further waves of IDS-TILDA will play an important role in generating robust data that will inform understanding of medical and social determinants of causality.

5.2 Comorbidities and cause of death

Morbidity burden and multimorbidity is known to be higher in people with an intellectual disability, and the profile of health conditions differs to that of the general population. [184] This is because physical and environmental factors associated with presence of an intellectual disability also increase the risk of physical and/ or mental health problems. People with an intellectual disability are more likely to have high body mass index, [185] be sedentary, [186] take multiple medications [187] and to live in congregated settings (where infectious diseases may be more prevalent). [188] Additionally, people with an intellectual disability experience inequities in both access to and outcomes of health service interventions. [189]

McCausfield et al. reported on the prevalence of chronic disease in the Wave 1 IDS-TILDA sample, and found that in contrast to the general population, illnesses associated with limitation of life expectancy in order of prevalence were mental health disease, neurological disease, gastrointestinal disease, endocrine disease, cardiovascular disease, lung disease, cancer, stroke, and liver disease. [41] In the End-of-Life Care study, in keeping with Wave 1 trends, further increases in prevalence of mental health disorder and neurological disease are observed. However, in contrast to Wave 1 trends, new diagnoses of cancer and respiratory disease led to increasing prevalence of these conditions.

The data highlight the difference between the comorbidities experienced by the population of people with an intellectual disability and the general population. They serve as a reminder of the importance of disease prevention and management pathways prior to the terminal phase of illness to maintain wellbeing and improve outcomes for as long as possible. This includes consideration of incorporation of a palliative care approach, as early as possible in the course of chronic, incurable disease. [190] Early integration of palliative care is important because people may experience distress at any point in the disease trajectory and because refractory symptoms at the end-of-life often have their origins at earlier stages of illness. A dual-pronged approach to service delivery should therefore be taken where strategies to minimise potentially avoidable causes of death as well as strategies to provide palliative care are adopted.

Sudden death

IDS-TILDA End-of-Life survey data revealed that 4.2% (n=3) of people with an intellectual disability died suddenly and unexpectedly, having been perceived by respondents to be well prior to death. Higher rates of sudden death have been noted in the population of people with an intellectual disability compared to the general population. [51, 191] The term 'sudden death' (also called sudden and unexpected natural death) refers to those deaths that are not preceded by significant symptoms and it excludes violent or traumatic deaths. While the World Health Organisation definition of sudden death is a death 'occurring within 24 hours after the onset of symptoms' there is no universally agreed time period leading to challenges in understanding and interpreting epidemiological data.

Cardiac death accounts for approximately 90% of sudden death in the general population; its incidence increases with age, varying from about 1 per 1000 per year in individuals of 35–40 years, 2 per 1000 per year by 60 years, and 200 per 1000 per year in the elderly. [192] In the population of people with intellectual disability, sudden unexpected deaths related to epilepsy are higher than the norm [193] but sudden death from cardiac or intracerebral events may of course also occur.

The findings of the IDS-TILDA study are therefore in keeping with those previously noted in the literature, given that 4.2% died suddenly and unexpectedly. As previously noted, two of those deaths were due to cardiac events, and the cause of the remaining death was not known despite post-mortem. In particular, no significant difference was noted between the findings of the IDS-TILDA End-of-Life Study and the UK VOICES study involving sudden deaths of people with an intellectual disability, χ^2 (1, N = 220) = 0.10, p = 0.75. [194]

It is worth noting that 15% of participants were reported as dying suddenly before Wave 3 in the TILDA study of the general population. [195] However in the TILDA report, a sudden death was described as being associated with a period of illness of less than one week- when this period is examined in IDS-TILDA, no significant difference is noted between participants as 14.1% (n = 10) of IDS-TILDA participants died within one week of onset of illness, χ^2 (1, N = 446) = 0.03, p = 0.85.

Expected deaths and length of illness

The majority of deaths were expected. Data from the United Kingdom estimates that 75% of the general population with chronic illness experience a period of ill-health prior to death. [196] [192] TILDA has similarly found that 71% of decedents from the general population were unwell for one month or more before death. [195, 197] In contrast, Hunt et al's UK nationwide population-based post-bereavement survey of people with an intellectual disability between 2013-2014 found that 55.8% of the total sample were unwell for one month or more. [198] Data from the IDS-TILDA End-of-Life Care study on length of illness more closely resembles that of the general population of Ireland and the UK, than the population of people with intellectual disability of the UK, because nearly three-quarters (69%; n = 49) of IDS-TILDA End-of-Life Care study decedents were reported as unwell for a period of one month or more before death.

The findings therefore demonstrate that there is broadly similar recognition of illness at a point in time one month or more before death between the population of people with an intellectual disability and the general population in Ireland and England, compared to recognition of illness in people with an intellectual disability in the UK. In particular, a chi-square test of independence was performed to examine the difference in the time from illness recognition to death between IDS-TILDA and TILDA participants, and reported no significant difference, X^2 (1, N = 446) = 0.10. p = 0.74.

When the time point of six months before death is examined, although the UK-based data suggests evidence of delayed recognition of illness (55.7% of the UK general population sample and 34% of the UK-based population with an intellectual disability, p<0.05), the same difference between populations is not seen in the Irish data. The IDS-TILDA End-of-Life Care sample found that 40.8% (n=29) were reported as unwell for six months or more compared to 50% (n= 187) of the TILDA End-of-Life Care sample but this difference was not found to be significant, X^2 (1, N = 446) = 2.06, p = 0.15.

These findings are noteworthy given that the literature has highlighted concerns relating to issues of delayed or late diagnoses. The comparability of TILDA and IDS-TILDA findings is of some reassurance. A recognisable period of illness before death allows time for care planning and provision of palliative care- the fundamental importance of this factor and the difference noted between Irish and UK data in this area led to its inclusion in the second iteration of the ID PC ecosystem model (Figure 5). Timely recognition of serious illness is important in terms of treatment options, and accompanying palliative care needs are prerequisite to care planning, and increased complexity associated with lack of planning or foresight. It is a positive finding that staff were able to identify duration of decline in the Irish setting, but further work is required to ascertain whether palliative care needs assessment invariably accompanied the recognition of illness as would be indicated by best practice.

Cause of death

Respiratory disease was the most common cause of death, accounting for 22.5% (n=16) of deaths, followed by cancer (19.7%; n=14) and dementia (18.3%; n=13). It should be remembered that 18.3% (n=13) respondents did not know what cause of death was listed on the death certificate and given the proportion of missing data relating to this item, findings should be interpreted with caution. While the causes of death are in keeping with intellectual disability literature, [180, 184, 198] they do however contrast with findings from the TILDA End of Life study which found that the most common causes of death were cancer, cardiovascular disease, respiratory diseases and severe infectious diseases, with 10% classed as 'other'. [6]

Given that palliative care, in the general population has been more commonly associated with the care of people with cancer, it is important to consider how well staff and services are prepared to care for people with non-malignant disease, so that people with an intellectual disability do not experience the cumulative disadvantage of the presence of impairment and a non-malignant diagnosis. To date, greater focus has been given to identifying and addressing the palliative care needs of people with an intellectual disability and dementia, compared to people with an intellectual disability and respiratory disease. The studies that have been conducted offer practical value in shaping service response. For example, Fahey-McCarthy et al. developed an education and training programme to support caregivers of people with intellectual disability and dementia. [199] Jokinen et al. developed guidelines for structuring community care and supports for people with an intellectual disability affected by dementia. [199] It is suggested that similar resources tailored to the needs of other cohorts would be of value.

5.3 Community-based service utilisation in the last year of life

Overall, the level of input required to support individuals in the last year of life was high. Only 7% (n=5) individuals did not have staff support in their home environment. The majority, 79.1% (n = 53), required full or part-time nursing input. This is in contrast to the TILDA End of Life Study in which 57% received supports in the home setting X^2 (1, N = 451) = 35.90, p = 0.00001.

Data demonstrated that use of community-based services was variable. In keeping with the experience of the general population, overall service utilisation increased. However, the increased use of services was not uniform and access to several community-based services remained low. Significant increases in use of social work, occupational therapy, dietetics and speech and language therapy were observed reflecting changed physical, functional, and emotional needs. Dietetics was the service accessed by the largest proportion of decedents (67.6%), with similar proportions of decedents accessing speech and language therapy (55.9%) and occupational therapy (57.4%). Baseline physiotherapy access was reasonably high at 44.1% but a significant difference in this was not noted, which may indicate limited consideration of rehabilitative palliative care in care provision.

Although the data indicate that over half the decedents received religious support and input, the qualitative interview content largely focused on the degree to which individuals participated with Roman Catholic religious rituals and the conduct of funerals and services of remembrance and the role of pastoral care in supporting peers in bereavement. As Laqueur observed, 'Care of the dead has been regarded as foundational – of religion, of community, of civilisation itself' [200] Nonetheless, Ireland has long been regarded as notable for the level of community engagement that is observed in funeral rituals and observances. [201] A central part of Ireland's cultural tradition is that in bereavement, the community rallies around the family to support those mourning and to celebrate the life of the deceased. The wake is a key part of the death customs; it takes place following preparation and placement of the remains of the decedent in a coffin and usually happens at the person's home. Relatives and friends visit and pay their respects and are provided with hospitality. Prayers may be said (most commonly the Rosary for Catholics). The wake complements the funeral service as it provides opportunity for focus on the individual's life, while the funeral focuses on death and possible after-life, according to individual beliefs.

Only one interview commented on the role of the priest in speaking of dying and death to the person with intellectual disability before the individual's death. It appeared that the respondents recognised the importance of spirituality but largely supported this by facilitating religious practice rather than more direct personal engagement with the individual. The finding points us to further consideration of the observation made of spiritual care for the general population- that is an intrinsic and essential component of palliative care, yet the least developed and most neglected dimension of palliative care. [202] While it is possible that pastoral care or other team members such as psychology or social work did carry out such work unbeknownst to the study respondent, the topic merits further exploration in future waves of the End-of-Life Care study. As indicated by the findings of the literature review, research on spiritual care for people with intellectual disability is lacking, despite people with an intellectual disability indicating that this is a topic of importance when participating in studies. [79, 84, 95, 203] Further study is therefore warranted.

5.4 Acute hospital service utilisation

The survey data demonstrated that hospitalisation in the last year of life was common with 69.1% (n = 47) hospitalised on at least one occasion.[12] This contrasts with data collected on Emergency Department presentations in IDS-TILDA Wave 1 data collection, when only 24% (n=17) of the sample attended the hospital. Increased hospitalisation in the last year of life is also seen in TILDA, although TILDA usage is higher with frequency data showing a mean of 1.3 Emergency Department patient attendances.

Overall, generally positive experiences of hospitalisation were reported in the qualitative interviews. This is also important, as in the past, people with an intellectual disability have often been reported to have poor hospital experiences.[51, 204] The identification and examination of services that demonstrate positive deviance provides future opportunity to characterize and disseminate strategies for improving quality.[205] Known causative factors of poor hospital experiences that have been documented in the literature include the negative attitudes of staff, delays in diagnostics and treatment, and reliance on family and paid carers for advocacy and provision of care.[206] In this study improvements were commented on in the areas of communication, access, and staff attitudes, but a persistent need for carer advocacy and support was described by respondents. Financial constraints appeared to be a growing threat to the ability of organisations to release staff to provide in-hospital support which may compromise the gains made to date and means that this area merits attention from a practice perspective.

5.5 Care transitions in the last year of life

5.5.1 The importance of place of care for service users with advancing illness

Moving home is an event experienced by both the general population and people with an intellectual disability at different stages of life. However, unlike the general population, many people with an intellectual disability in Ireland experienced segregated institutional living,[207] and its legacy persists. Ireland is pursuing the policy goal of ensuring the people with an intellectual disability have the choice to live in community home settings, but achievement of this goal has been slow as evidenced by the significant proportion of individuals in IDS-TILDA End-of-Life Study who lived in residential care. The challenges of 'ageing in place' add further complexity to the topic.

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[12] [3 missing data n=3; valid percentage reported].

The premise of ageing in place is that helping older people to remain living at home fundamentally and positively contributes to an increase in well-being, independence, social participation, and healthy ageing. [208] While studies have demonstrated the benefits that can be associated with ageing in place, they have also drawn attention to the downsides that can also accompany living as an older person at home and that are exacerbated by inadequate infrastructure, supports and community engagement. [209, 210] IDS-TILDA has provided valuable data on changing demographics and housing mobility in Ireland. Over the 10-year period between Wave 1 and Wave 3, 32% (241/753) of participants experienced a change in their living circumstances. There was an increase in more supported moves at Wave 3, 24% (40/167), up from 13.3% (16/120) at Wave 2. Physical health changes were more likely to be reported as the main reason for these moves. Most participants who moved were reported as being happy following the move although many individuals with intellectual disability were not involved in the decision to move.

5.5.2 Experience of transitions of care

The End-of-Life Care study provides new information on care transitions that occurred in the last year of life. As noted, nearly three quarters of decedents lived in residential care settings, with nearly one quarter living in community group homes. While maintenance of a familiar environment was felt to be very important, the needs associated with advancing illness meant that some individuals moved home in the last year of life. Nearly one-half of participants had been unwell for six months or more (40.8%; n = 29) and 15.5% (n = 11) of decedents experienced a change in their place of care. Four moved out of the ID service to nursing homes, while seven remained within the ID service but moved to higher support units there. When moves occurred, staff had generally tried to delay the move for as long as possible and had often significant sacrifices in attempting to sustain care. Decisions to move were eventually made based on service users having increased care needs that either could not be met in their usual place of care or within available funding.

From the quantitative and qualitative data, it appears that additional resourcing or improved physical infrastructure might facilitate some greater number of individuals to be cared for in their usual place of care in the last year of life. However, in some cases, the challenges to maintaining usual place of care appear more difficult to resolve- for example, in situations where the care of other residents is impacted by the increased needs of the person with advancing illness, or where significant input from healthcare staff is required in a social care environment. These challenges have been noted internationally also, and there is consensus that given anticipated demographic changes, there is a need to ‘plan ahead’ and consider issues of home adaptations, staff training and support and to integrate more collaborative principles in decision-making about place of care with people with an intellectual disability and their fellow residents. [211]

Of some reassurance, in most cases it appeared that transitions of care were managed well and that the subsequent care that was provided was ‘excellent’. However, there were some cases which staff regarded as failures of person-centred care and which they felt were associated with poor outcomes. Such experiences make clear the need to ensure that adequate and appropriate resourcing and systems are in place so that meaningful choices are available to people with an intellectual disability with advancing illness and that decisions are made considering preferences and needs.

5.5.3 Place of death

Studies involving the general population are reported as demonstrating that most want to not only live, but also die at home- although it is important to note that home is the majority preference as place of death only when missing data are excluded. [212] Preferred place of death is a complex topic, as preferences may change over time, patient and caregiver preferences may not be congruent and there are circumstances in which dying at home may not be feasible. [213] It is now recognised that there are both positive and negative aspects to end-of-life care in all settings [214] and the relative importance given to place of care at the end-of-life varies between individuals. [215, 216] Nonetheless, it remains an important factor in achieving a ‘good death’ for many, and it is unsurprising that place of care and place of death emerged as important themes within this study also.

IDS-TILDA participants placed high value on continuity of care and place, and home was achieved as the place of death for 50.7% of decedents. This stands in contrast to findings from TILDA where only 27% of general population deaths occurred in the home setting [195, 197] but echoes the findings of the UK-based VOICES-SF study who found that found that 49.7% of adults with intellectual disability living in residential care died in their usual place of care. [198]

A further finding of interest relates to hospice as place of death. In contrast to the UK-based VOICES-SF study, but in keeping with trends seen in the general population in Ireland, hospice appears to have substituted for hospital as an alternative place of care. Approximately 6% of deaths in Ireland occur in hospice settings [217] and the IDS-TILDA End-of-Life Care study similarly found that 7% of decedents died in a hospice. No decedents died in hospice settings in the UK-based VOICES-SF study. The qualitative data further revealed that there was strong endorsement for home and hospice as the 'right' places to die while unsurprisingly opinions about hospital as the place of death were more mixed.

A significant body of literature has accumulated describing how staff working in intellectual disability services want to help people with an intellectual disability die in their preferred place of care (usually their home setting) but to date, much of the emphasis of the literature has been on barriers or deficiencies in care provision. [218] Despite challenges inherent in providing care, data from both this study and the UK-based VOICES-SF study found that a greater proportion of people with an intellectual disability achieve death in their familiar home setting compared to the general population. Notably, the likelihood of dying at home was significantly increased when the community palliative care team were involved in care, and this will be discussed further in section 5.7. The data further demonstrates that patterns of admission to hospice track those of the general population, unlike in the UK. This suggests a degree of successful integration with specialist palliative care services in the Irish setting that has not been noted to date elsewhere. It also suggests that ID service capability to provide care that supports people at end-of-life in their home setting is developing. Additional data on quality of care is important to considering this further, as home is only an advisable place of care if services meet individual needs and are of good quality; this will be considered further in the remaining two sections to this chapter.

The data also provides some preliminary corroboration of findings from research involving members of the general population which suggests that choice regarding place of care should not simply be viewed in a dichotomous manner (i.e., wanted/ not wanted) but rather in a more nuanced manner where a range of preferences exist, some better than others. [219] In such a conceptualisation, achieving a 'second-best' preference is not viewed as a failure in the manner in which a 'not at all preferred' option would be. For example, while a preference to remain at home may be the preferred option, if circumstances unfold in ways which mean that this option is not feasible (e.g., uncontrolled symptoms requiring specialist input) then achieving the 'next best' option of care in a hospice may be viewed favourably and the 'least preferred' option of hospitalisation avoided.

5.6 Palliative care needs

As previously stated, people with an intellectual disability frequently experience unmet healthcare need and experience poorer outcomes than the general population. While people with an intellectual disability are 'people first' and as such, share more similarities with the general population than differences, better understanding of the palliative care needs of people with an intellectual disability should allow lead to improvements in needs assessment and care provision. The IDS-TILDA End-of-Life Study makes a distinct contribution to the literature by gathering nationally representative data from a wide range of staff members who had experience of being involved in end-of-life care. The data generates both in-depth and generalisable understanding of the ways in which the presence of impairment (or the social consequences of impairment) impact on the experience of life-limiting illness for patients, staff, and families. The findings are in keeping with the typology of palliative care needs identified through Chapter 2's integrative literature review. They provide additional supporting evidence for the validity of the typology and point to areas of common experience between Ireland and other countries. The findings further illustrate micro-, meso-, exo-, macro- and chronosystemic influences on complexity of palliative care need in keeping with the proposed model of the Intellectual Disability Palliative Care Ecosystem.

5.6.1 Time and continuity of care

The data again demonstrated the importance of trust, continuity of care and 'knowing' the individual to the establishment of a therapeutic relationship with the person with intellectual disability. While this was regarded as being important for all caregivers, time to form a relationship was something that staff outside of ID services did not always have available to them. ID staff continued to be influenced by the traditional association of palliative care with end-of-life and this was associated with late referrals to specialist palliative care. Organisation of SPC services meant that that several team members commonly were involved in the provision of care to any one person with intellectual disability rather than one key worker. It was notable that SPC staff themselves did not appear to always recognise the need for time given that ID staff reported occasions where the SPC staff had declined early engagement despite the requests of ID staff.

For the general population, SPC staff are skilled in fostering 'swift trust' in time-constrained situations, and organisational artefacts (such as reputation or expertise) may be used as a substitute for personal contact when establishing relationships. [220, 221] However, these artefacts may have little meaning for people with an intellectual disability who are not abstract thinkers. Equally, management continuity does not appear to substitute for relationship continuity, [222] as it is only through knowing a person that carers can truly understand the individual and their world. [223, 224] All of this means there is no ready substitute for time, and this highlights a specific need that should be considered within the generalist-specialist model of palliative care provision. The importance of 'knowing' the individual underscores the value of GPs and ID service providers developing generalist palliative care capabilities so that they can effectively act as the first line of care provision. Given that individuals with more complex need will require the input of specialist palliative care teams, consideration needs to be given to the ways in which those services operate. Delivery may need to be reorganised to safeguard the time to develop effective relationships, staff may need to be educated to better understand the need for relational continuity and how to better manage communication when relying on proxies.

5.6.2 Psychosocial distress and familiarity of place

The living arrangements for people with an intellectual disability vary widely depending on capabilities and options. As noted in the literature review, high value is placed on familiar places of care for several reasons – people with an intellectual disability often have limited social networks and strong ties may have developed with fellow residents; staff are skilled in communication while staff in other settings lack comparable expertise; and there is a sense of comfort and security associated with 'home'. [2, 211] Place of care, therefore, assumes particular importance in the context of caring for a person with intellectual disability with life-limiting illness. IDS-TILDA End-of-life Care study findings confirm the findings observed in the literature and emphasise the priority that ID staff give to this issue. Given that only two of the study decedents had lived in family homes prior to death, the data cannot yet provide insight into the needs or care transitions of this particular cohort- however it is anticipated that later waves will address this shortcoming.

While 'home' is often the preferred place of care for the general population, the particular importance of familiarity and safety for the population of people with an intellectual disability should be carefully considered by all stakeholders when making decisions about place of care. When it is not possible to maintain a person in their familiar setting, this study's findings have shown that it can nevertheless be possible to achieve positive outcomes. The qualitative data describes the efforts that were made in such situations to plan and manage transitions of care that included staff staying with clients when they were hospitalised or having key workers move with clients when they were re-located within organisations. The findings provide additional insight into the management of transitions of care (successful or otherwise) and this is considered further in section 5.6.

5.6.3 Physical distress and impact of communication impairments

Inability to communicate makes the treatment of medical issues difficult and this extends to palliative care. Communication impairments make it hard to identify the nature of distress and in situations where self-reports cannot be obtained, communication depends upon carers' ability to translate a language of signs and behaviours. ID staff have an advantage in that they 'know' the individual, and so can recognise distress cues. IDS-TILDA End-of-life Care study data demonstrates the frustration experienced by ID staff when they encounter other non-trained ID staff who are unwilling or unable to recognise distress. It also shows that despite their experience, ID staff expressed reservations about their ability to accurately make assessments in all situations. As demonstrated in the literature review, previous work in Ireland has revealed similar findings, where both ID and SPC staff feel less confident and capable in alleviating suffering in the palliative care setting.

The solution that has been commonly proposed is that staff will need to develop partnerships where each specialty contributes equally to assessment and management. However, as noted in both the literature review and IDS-TILDA End-of-Life Care study data, partnership working does not always guarantee successful outcomes. [85, 102, 225] It is therefore important to consider ways in which collaboration may be strengthened or improved going forward. Strategies to foster this collaborative approach may include interacting on a staged basis with longer periods of time allowed and actively reflecting on practice and team-working. The topic of partnership working will be considered further in section 5.7.

5.6.4 Emotional distress and impact of communication impairments

Western healthcare systems consider that offering individuals the opportunity to have open and honest communication about their diagnosis is a basic right. This extends to discussions about terminal illness, while acknowledging that communication opportunities should be proactive but sensitive and should take account of preferences and ability to engage. However, as noted, people with an intellectual disability are afforded fewer opportunities to participate in conversations than members of the general population. [2] This has largely been attributed to staff lacking skills and experience to talk about serious illness and death, and to be fearful of initiating conversations on these matters. [85, 90, 102, 225] These challenges were evident in IDS-TILDA End-of-Life Care study data; importantly it clearly remains a challenging area of practice with little consensus on best response.

Surprisingly little work has been carried out on how people with people with an intellectual disability conceptualise illness and death, but it is thought that many do have awareness of these life experiences. [226] The way in which death and bereavement are experienced is thought to be dependent on both intellectual and socio-emotional age. [227] This points to the importance of considering social networks, life experience and relationships as well as biology and temperament in development. Although the literature endorses the right of people with an intellectual disability to know about the end-of-life, in practice it appears that they are often afforded little opportunity to acquire this knowledge. [2] The consequence of closed communication is that people with an intellectual disability are frequently not involved in decisions relating to their end-of-life care. Moreover, the failure to provide them with the chance to speak of their wishes, worries or concerns may result in missed opportunities and heightened anxiety. This study's findings demonstrate that there continue to be missed opportunities for people with an intellectual disability in Ireland.

Although communication is a challenging and complex area of practice, decisions about communication should be made in the same way as those that concern the general population; the decision-making process should be grounded on ethical principles while considering individual circumstances. Specifically, as part of the individualised assessment, carers should make assessments of the person's levels of emotional and conceptual understanding of illness and death. Although resources have been developed by Stancliffe et al. to assist in assessment of knowledge and attitudes about end-of-life [219] respondents in the IDS-TILDA End-of-life Care study did not demonstrate awareness of formal methods of appraisal. Given that many people with an intellectual disability have communication impairments, if communication then take place, it should be undertaken on a gradual or staged basis, and time should be spent building a relationship of trust. [31] Strategies to support conversations should include carrying out an assessment to understand whether the person is capable of abstract thought. Staff should explore previous experiences of loss, ill-health, and death, identify coping mechanisms, and actively support understanding of illness and exploration of feelings. While training has an important part to play in improving care, it has been noted that education alone is not sufficient and that staff need support that should include reflective practice, supervision and team discussion. [104]

Decisions that carers make on behalf of people with an intellectual disability can be made without proper attention to ethical issues. [113] All professionals need to have knowledge of applicable legal frameworks, be trained in capacity assessment and be knowledgeable about methods to support decision-making. The Intellectual Disability Palliative Care Ecosystem model highlights the important influence of personal characteristics in areas of palliative care need, such as decision-making. The IDS-TILDA End-of-Life Care study findings make a further original contribution by highlighting the influence of the emotional dimension of decision-making. Staff working in ID services demonstrated a keen desire to support engagement of people with an intellectual disability in other areas of life, and to provide care that was respectful of will and preferences while meeting best interests. However, when it came to end-of-life communication and decision-making, strong protective instincts appeared to dominate. Decision-making is not an entirely rational process; while the heuristics and tendencies of unconscious decision-making have been studied in other healthcare areas, [228, 229] little attention has been paid to them in this field to date. The importance of heuristic decision-making as a variable that influenced staff decision-making, led to its inclusion in the version 2 of the ID PC ecosystem conceptual model (Figure 5). Further exploration of this area would be of value and could, for example, lead to the development of interventional strategies to support self-awareness and improved decision-making. [230]

Additionally, the data pointed to the importance of spirituality as a source of support or strength to people with intellectual disability. Although this finding was consistent with previously published literature, [79, 84, 112] the fact that this is an under-explored area in the literature has meant that its significance was not fully realised in the development of the first iteration of the ID PC ecosystem model and it was not included as an ontosystem variable for people with intellectual disability. The importance placed on spirituality by a number of respondents in the study led to its inclusion in the revised model and signals that this is an area that merits further study in future waves of IDS-TILDA (Figure 5).

5.6.5 Physical disabilities, sensory disabilities, and challenging behaviour

Respondents commented that physical and sensory disabilities and challenging behaviour are needs that persist (and sometimes intensify) in the context of a life-limiting condition. Challenging behaviour often results from the interaction between personal and environmental factors, with inability to communicate prominent among the multiple factors that may provoke it (e.g., a need to attract attention, a way of avoiding demands). The need for ongoing specialist support and intervention services may act as a barrier to access to hospice admission, given that the environment may not be appropriately modified. While the finding that 6% of decedents were admitted to hospice for end-of-life care is of reassurance, it is important to recognise that the need for admission to specialist palliative care units for symptom control, psychosocial support or respite can also arise at earlier points in the illness trajectory. Challenging behaviour or complex need relating to disability is more likely to act as a barrier at those earlier timepoints (as declining physical performance status at end-of-life means that a person is more likely to be bed-bound or poorly conscious). As such, it would be of value if further exploration of hospice utilisation at earlier points in the disease trajectory was conducted.

5.6.6 Emotional and psychosocial distress of peers

Discussion about the needs of other people with an intellectual disability who are part of the individual's social network focused mainly on support at the point of death and in the bereavement period. This is in keeping with Irish focus group findings on this topic that confirmed that staff show significant variation in how they provide support to peers but that most commonly support is reactive rather than pro-active. [49] The preparation that a person with intellectual disability receives for the impending death of a peer may be minimal because of a culture of closed communication about illness. Although this may be undertaken to protect the person from anxiety, it runs the risk of making their grief a more acute experience, and the development of long-term mental health problems more likely.

Dealing with death and bereavement is difficult, and people with an intellectual disability are particularly disadvantaged when facing this challenge because of social exclusion, disempowerment, and impairments of cognition, adaptive skills, and communication. It is advisable that carers engage in forward planning focused on the needs of peers whenever a loss is anticipated to reduce the risk of complicated bereavement reactions developing. While preparation for loss and change is not an easy option, it is one that can lead to increased emotional growth, self-awareness, and empowerment. [231] Carers should therefore sensitively support these peers to maintain friendships with their peers, even towards the end-of-life, to ensure they are enabled to participate in all aspect of the life cycle, including death.

The qualitative interviews provided rich insight into the fact that ID staff commonly facilitated the involvement of fellow residents in the days before death and in funeral rituals. It provides reassurance that such approaches are feasible and, indeed, were regarded as promoting understanding and healthy grieving by ID staff. The successful involvement of peers at these times provides a sound basis for extending practice and considering earlier and more proactive approaches to inclusion and support. The importance of this topic area resulted in its inclusion as an additional macrosystem theme in the second iteration of the ID PC ecosystem model (Figure 5).

5.6.7 Emotional and psychosocial needs of families

Many people with an intellectual disability are supported by their families and this is likely to increase in the future. Care needs intensify following the diagnosis of a life-limiting condition and family members may need support to carry out their caring role. Family members may also be emotionally affected and, as far as possible, their needs for support should be met. Interview data revealed that ID staff were aware of the impact of illness on family and tried to support them by providing them with information and ‘being there for them’ although no formal supports for families were identified outside of specialist palliative care services. This raises an important question in terms of quality of bereavement support available in general palliative care settings. The National Clinical Programme Model of Care for Palliative Care states that four levels of bereavement need may be identified- universal grief needs, organised support needs, professional counselling needs and complex grief needs. It points to the importance of ensuring that bereavement services are organised on a population-planned level- this means that while every organisation should not provide bereavement services, ID organisations should be able to signpost individuals to appropriate services when required. [232]

It is notable that only three of the interview respondents were family members of the decedent, reflecting the legacy of family separation and institutional placement experienced by many older adults with an intellectual disability in Ireland. Further exploration of the direct voice of family members is warranted in future waves of IDS-TILDA.

5.6.8 Emotional and psychosocial needs of staff

Although ID staff are professional caregivers, the majority of respondents in the IDS-TILDA End-of-Life Care study had established long and close relationships with decedents. Notably, the average length of relationship was 11.3 years, and it was evident that sometimes respondents were the people with whom the person with intellectual disability had the closest relationship. This meant that staff were understandably affected when a resident became unwell and there was a strong desire to provide care for the person to the best of their ability for as long as possible. The natural sadness that staff experienced because of the illness of the person with intellectual disability could be compounded by staff shortages, and the responsibility of meeting both the needs of the unwell resident and other service users. A sense of lack of competency added further strain. The findings are in keeping with those of the integrative literature review and the Intellectual Disability Palliative Care Ecosystem model and underscore the importance of considering the emotional and bereavement needs of ID staff when developing the model of palliative care provision for people with an intellectual disability.

5.6.9 Consideration of population-specific needs

As described in the literature review findings and confirmed by the IDS-TILDA End-of-Life Care study data, specific palliative care needs of people with an intellectual disability arise because of the interplay between the presence of impairment or the social consequences of impairment and the presence of a life-limiting condition. The identified needs are important because they highlight areas where SPC and ID services can fail to meet the needs of people with an intellectual disability. Understanding where and why change is required leads us to think about what changes might be made to improve care. There is, of course, overlap between areas of need because human nature is complex but using the typology of needs in a systematic way helps us understand where barriers should be addressed and supports put in place.

For example, the typology directs attention to areas that are currently relatively neglected in practice such as direct communication and engagement with the person with intellectual disability or consideration of their spiritual care needs. It also ensures that peers with intellectual disability, family members and caregivers are all considered in needs assessment and care planning. All organisations, including palliative care services, should strive to nurture a culture that ensures the continuous improvement of high quality, safe and compassionate healthcare. Recognising the specific palliative care needs of people with an intellectual disability is a necessary first step towards ensuring that services and staff have the capability to respond effectively to those needs and impact on outcomes. Despite the Report of the National Advisory Committee on Palliative Care pointing to the need for the specific needs of the population of people with intellectual disabilities to be met, [19] efforts to tailor service provision remain variable and occur at local, rather than national, level. Effective leadership, ensuring that the voice of the person with intellectual disability and their family is heard at every level, and adjusting service delivery so that complexity is understood and responded to, are the actions that now need to happen.

5.7 Palliative care provision

The finding that 43.6% of the population accessed SPC is particularly important given that the literature has previously reported that people with an intellectual disability experience inequities in access to palliative care. [2] Due to limitations in national data collection, a comparative figure is not available for the general population. [217] Moreover, place of death was strongly associated with the involvement of a community palliative care team. Interestingly, 60.5% of those who were not receiving community palliative care died in hospital, while only 19.2% of those who were receiving community palliative care died in hospital.

In contrast to previous studies, this study has demonstrated relatively high levels of access to SPC services by older people with an intellectual disability. Hunt et al. [191] found that 18.2% of decedents received care from community palliative care and no decedents received in-patient palliative care; this stands in contrast with the 40.8% reported in our sample to have accessed specialist palliative care. As this study did not collect data on receipt of hospital based SPC, it is likely that additional numbers of people with an intellectual disability accessed those services. It is notable, however, that SPC services were often accessed late in the illness trajectory notwithstanding some desire on the part of ID staff to have earlier integration of care. Despite efforts to ensure that patients are afforded the opportunity to receive earlier access to SPC services, the trend towards later referral is one that is also seen in the general population.[233, 234] Potential benefits from earlier referral to palliative care have been described, at least for people with metastatic cancer, and include better symptom management and longer survival.[235, 236] A recent National Institute for Clinical Evidence review observed that the quality of evidence of evidence is however poor as the specification of supportive and palliative care services varies widely, and the elements of care provided to intervention and control groups in studies are not described.[237] In addition, the definition of early or late referral also varies. The review raises important questions for the provision of palliative care to people with an intellectual disability; the integrative literature review and the End-of-Life Care study data would suggest that early referral would have particular value in this population, but this hypothesis should be tested further.

In common with a number of countries, the model of care for palliative care in Ireland[21] adopts a coordinated palliative care model where the primary care physician or treating specialist can manage many palliative care problems and initiates a specialist palliative care consultation for more complex or refractory problems. In this model, specialist services are provided based on need, and collaboration plays a critical role in ensuring that networks of services function effectively. Reassuringly, this study's findings provide evidence that partnerships between SPC and ID services have developed over time. Several factors conducive to good partnership working were described by respondents that are likely to have contributed to this: a shared ethos of care, ease of access to SPC services, good communication, and the presence of mutual respect, trust, and expertise. Importantly, these factors are ones identified within the Intellectual Disability Palliative Care Ecosystem model as being ones that reduce complexity of care.

However, respondents did point to some challenges that have been previously noted in other studies and the integrative review. These include a certain lack of clarity around respective roles and responsibilities, and unequal participation in decision-making.[38, 238, 239] Additionally, the issue of 'elite practice' was evident. This term was first used by Walshe et al.[124] to describe specialist palliative care services which are perceived to cherry-pick or restrict service provision. In Walshe's study, elite practice was noted to lead to situations where the services are perceived to be unhelpful and referral rates eventually fall. Although respondents were more positive than negative in their appraisal of SPC services, the ambiguity that has been highlighted in the respective roles of SPC and ID staff in the provision of palliative care merits attention. The projected demographic pressures of an ageing population are expected to lead to increasing demands for SPC services, [16] which will likely place new strains on relationships and exacerbate these issues.

To what extent can the palliative care needs of people with an intellectual disability be met by ID services alone? To what extent is the input of specialist palliative care services required? These are questions that are fundamental to the development of palliative care provision for people with an intellectual disability, but which have not yet been answered. As Chapter 2's integrative literature review findings demonstrate, while some elements of complexity may be recognised objectively, others are experienced subjectively. It appears that these elements of complexity are not readily apparent to those who lack an in-depth understanding of the Intellectual Disability Palliative Care ecosystem. The fact that experience and complexity of need are shaped by a variety of factors operating at different levels and interacting in complex ways means that recognition or management of palliative care need does not lend itself to traditional 'reduce and resolve' [257] management approaches. The application of the Intellectual Disability Palliative Care ecosystem an explanatory model for understanding the nature of the system offers opportunity to direct and catalyse change and transformations within the healthcare system.

The findings of the IDS-TILDA End-of-Life Care study provide evidence of desire and improved capability within ID services to provide care. It is an noteworthy observation that respondents rated the quality of palliative care provided to people with an intellectual disability highly whether SPC were involved in care provision or not. Sample size limitations meant that the cross-tabulations could not be explored more reliably, however future Waves of IDS TILDA will enable greater understanding of these important issues. Interestingly, Hunt et al. [191] reported that ratings of perceived care were positive despite the fact that SPC services were commonly not involved in care. It has been suggested that when respondents have experience of SPC services they are better able to rate service provision as they have a point of comparison [233] but it remains unclear from this study as to whether respondents had that prior experience or not. It would be of value to collect such data in future Waves of IDS TILDA and to explore in more detail aspects of care provision, such as involvement of the person with intellectual disability in decision-making and communication. The importance of these domains are recognised in the European Consensus

Norms for Palliative Care for People with an intellectual disability [105] but this study demonstrated relatively low levels of explicit engagement with people with an intellectual disability in communication about death (19.1%) or in decision-making (22.1%).

5.8 Quality of care provided at the end-of-life

Quality of care provided in the last two days of life was rated highly by respondents regardless of care setting, but it should be remembered that these ratings are provided from the perspective of the caregivers and not the person with intellectual disability. Grindod and Rumbold [240] found that the attitudes of ID staff about place of death were linked to beliefs about whether dying is an event best managed by medically trained staff or not. The authors found that staff holding the 'medical' view of dying preferred clients to die in hospital. It is likely that underlying beliefs and values of the respondent similarly shape the perception of what 'good care' is, and we do not know whether respondent beliefs and values align with those of the decedents or not. Further exploration of this area is advised.

Respondents rated the care provided in hospice, hospital, and intellectual disability settings favourably (Table 2, chapter 3). When asked to rate their overall impression of care provided in the last three months of life, taking all services into account, respondents reported that 64.7% of service provision was 'excellent'. Only 1.5% (n= 1) of respondents rated care as 'poor'. These ratings were provided despite the qualitative interviews revealing times where respondents would have been disappointed about aspects of care provision. However, it appeared that there were aspects of care that were valued in almost all situations which perhaps tempered ratings of care that might otherwise have been lower.

The aspects of care that are most associated with achieving a 'good death' in the general population are a sense of life completion, being free from suffering, being treated with dignity and respect, and being surrounded by family. [241] Those attributes have also been found to be important to people with an intellectual disability, with particular emphasis being placed on maintaining presence and relationships, communicating, and honouring wishes, and meeting spiritual needs. [79, 84] Respondents stated that pain relief in the last 2 days of life was 'excellent' in 60.3%, and that emotional and spiritual support were 'excellent' in 63.2% and 55.9% of cases respectively. A notably high proportion of decedents died at home or in hospice compared with hospital.

These findings are positive but is worth remembering that the interview data did point to concerns about responses to physical and emotional needs in earlier stages of illness and there would be value in further work exploring this given that survey ratings focused on the final days of life. Also, as previously noted, communication and engagement with decision-making was limited and this also merits further exploration. The IDS-TILDA End-of-Life Care sample studied largely comprised individuals with moderate, severe, and profound disability who were receiving residential care, and so it is possible that higher incidence of engagement may be observed in samples where there is greater perceived capacity to engage.

Although the person with an intellectual disability who is dying is the focus of care, it is important to remember that family members, peers with intellectual disability, and formal carers also are experiencing grief and loss, and response to their needs should be included in any consideration of quality-of-care provision. Failure to recognise and address their needs can lead to individuals experiencing stress and disenfranchised grief. Study findings revealed an ongoing need for attention to be paid to service responses for family members, peers with intellectual disability, and formal carers but these components of care are not assessed by the adapted VOICES-SF survey. Studying palliative care provision through the lens of the Intellectual Disability Palliative Care Ecosystem in future waves of IDS-TILDA may provide richer insights into experience and outcomes and may provide a theoretical basis for the development of interventional studies that include the clearer articulation of the service delivery components of general and specialist palliative care respectively and the stratification of service provision according to need.

Chapter 6. Conclusion

Summary

In Census 2016, people with an intellectual disability represented 1.4% of the population in Ireland. [242] Despite improvements in health and social care provision which have resulted in increased longevity and improved quality of life, they remain a disadvantaged group. People with an intellectual disability continue to die younger than their peers in the general population and to experience inequitable health care provision. [40] These inequities have been reported to extend to the provision of palliative care. [2] A call has been made for high quality evidence that maps current palliative care provision and investigates the quality of care provided, including how best practice might be achieved. [243]

IDS-TILDA is a longitudinal study studying the social, economic and health circumstances of adults with an intellectual disability aged 40 years and older who are resident in Ireland. [5] It is the only study able to directly compare the ageing of people with an intellectual disability with the general ageing population due to its unique methodology. Through the development of the IDS-TILDA End-of-Life Care study, an unprecedented opportunity has been offered to develop in-depth yet generalisable understanding of the palliative care needs and end-of-life care experiences of this population.

This thesis includes an integrative literature review of palliative care provision for people with an intellectual disability and presents findings from the IDS-TILDA End-of-Life Care study. Data synthesis carried out in the literature review led to the development of a typology of needs (Table 15) and a conceptual model of the Intellectual Disability Palliative Care Ecosystem (Figure 5), both of which provide a detailed and nuanced view of palliative care need. While previous reviews have emphasised that many of the palliative care needs of people with an intellectual disability are no different from those of the general population, this review points to the importance of including family, intellectual disability staff and peers within the 'unit' of palliative care provision. It also provides comprehensive description of the dynamic and inter-related contexts and variables that influence the development of need and complexity.

Table 15. Typology of palliative care needs

The needs of the **person with intellectual disability and life-limiting illness** related to: 1) Physical and personal care to ensure comfort and dignity. 2) Psychosocial care to ensure quality of life, social connectedness, and personhood. 3) Emotional care to ensure well-being and mental health. 4) Spiritual care to ensure peace and support. 5) Communication tailored to ability, preferences, and best interests. 6) End-of-life decision-making individualised to preferences, wishes, values and best interests. 7) Time and continuity of care to ensure security and well-being. 8) Ongoing attention to pre-existing needs related to impairment or the social consequences of impairment, tailored to the context of a life-limiting condition.
The needs of the **peers** of people with an intellectual disability related to a need for emotional and psychosocial support to help them cope with the experience of their peer's illness, loss, and grief; communication and informational needs; and the practicalities of minimising disruption and impact of another person's illness on their routines and quality of life.
The needs of **families** related to communication and informational needs; clinical decision-making and care planning support needs; emotional and psychosocial support to help individuals cope with loss and grief and the responsibility of shared decision-making; and practical supports to help them manage the care needs of the person with intellectual disability and life-limiting illness (e.g., financial, respite, carers, education, and training).
The needs of **staff working in intellectual disability services** related to communication and informational needs; clinical decision-making and care planning support needs; emotional and psychosocial support to help individuals cope with loss and grief and the responsibility of shared decision-making; and practical supports to help them manage the care needs of the person with intellectual disability and life-limiting illness (e.g., education and training, additional staff and resources, time to provide care).

Figure 6 Intellectual Disability Palliative Care Ecosystem v2 [13]

Microsystem themes:
- ‘Knowing’
- Time
- Normality

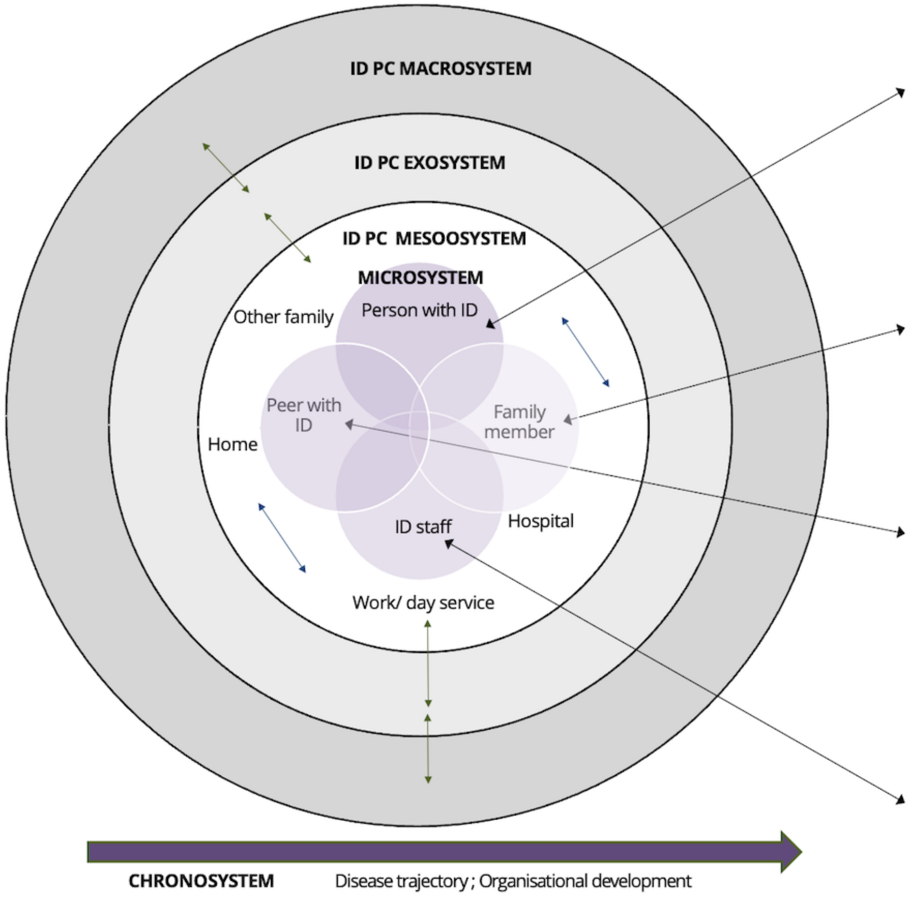
Mesosystem themes:
- Family-staff relationships
- ID MDT composition & working
- Broader system MDT working
- Availability & exchange of information
- Decision-making
- Training & experience
- Place of care & impact on peers

Exosystem themes:
- Resourcing
- Integrated care
- Recognition of illness and care planning
- Systems of information provision & decision-making

Macrosystem themes:
- Person-centered culture
- Mourning culture and practice
- Legislative environment
- Financing of care

Chronosystem themes:
- Disease trajectory
- Organisational development

PC needs of the person with ID (physical , psychosocial, emotional, spiritual, communication, decision-making, time & continuity of care, disability-related); PC needs of family; PC needs of ID staff; PC needs of peers



Person with ID ontosystem variables:
- Intellectual impairment
- Communication impairment
- Physical disability
- Functional decline
- Chronic illness
- Mental health
- Challenging behaviour
- Experience of a life of loss
- Experience and knowledge of death
- Spirituality

Family member ontosystem variables:
- Relationship
- Attachment & contact
- Caregiving responsibilities
- Prior experience of loss and death
- Coping capacity & resilience
- Self-efficacy
- Attitude towards HCP

Peer ontosystem variables:
- Intellectual impairment
- Communication impairment
- Care needs
- Challenging behaviour
- Living arrangements
- Relationship
- Prior experience of loss
- Resilience

ID staff member ontosystem variables:
- Relationship
- Prior experience of loss and death
- Heuristic decision-making
- Coping capacity & resilience
- Self-efficacy

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[13] [13] PC= palliative care; ID= intellectual disability; HCP= healthcare professional

Data from the IDS-TILDA End-of-Life Care study supported the typology of needs and conceptual ecosystem model. Further key findings from the improved understanding of mortality patterns, trajectory of illness and individual and system responses to palliative care need. The study confirmed respiratory disease as the most common cause of death and in contrast to other international studies found no evidence of delayed recognition of advancing illness. Encouragingly, at least 43.6% of the population accessed specialist palliative care services and 7% accessed hospice. Due to gaps in routine data collection for the general population, comparison figures are not available for the general population in Ireland but these figures are significantly higher than those reported in a national cross-sectional study of decedents with an intellectual disability in the UK.[191] High importance was placed on home as a place of care and death and 50.7% died in their usual place of care. A generally high quality of care was reported although the ratings were provided from the perspective of the caregivers only. Areas identified that merit further focused attention include communication, decision-making (including heuristic decision-making), spirituality, and support for peers, families, and staff.

Strengths and limitations

The IDS-TILDA End-of-Life Care study was nested within IDS-TILDA. Utilising a population-based sample and employing longitudinal methodology, both studies offered invaluable opportunity to explore and understand the many influences that shape the lives and deaths of people with intellectual disability. Longitudinal studies are powerful tools providing insights at both individual and group levels and establishing sequences of events over time. IDS-TILDA and the IDS-TILDA End-of-Life Care study are sister studies of TILDA and the TILDA End of Life study and as such, comparability between studies was possible and represented a key strength. Both studies represented the most comprehensive studies on ageing and end-of-life care to be carried out in Ireland. Moreover, they were the first of their kind internationally to be conducted in tandem.

The use of VOICES-SF as the survey instrument in IDS-TILDA offered further advantage because it allows for further comparability with other international studies that have used this tool. Of note, when VOICES-SF was used in a UK population-based study, the sample was drawn from social care settings only. In contrast, the IDS-TILDA End-of-Life Care study drew from the National Ability Supports System (NASS). As such, the IDS-TILDA End-of-Life Care study sample includes representation from people with intellectual disability across all settings of care, including family homes.

NASS is a national database that records information about Health Service Executive (HSE) disability-funded services that are received or required as a result of an intellectual disability, developmental delay, physical, sensory, neurological, learning, speech and/or language disabilities or autism. It is a comprehensive and high-quality dataset, but it is acknowledged that individuals with intellectual disability who are not in receipt of disability-funded services are not represented in the database. As such, the IDS-TILDA study population was a close, but not full match for the population of people with intellectual disability in Ireland.

A further potential limitation of this study was that while the 66.4% response rate is high, there may have been differences between the data reported here and the remaining respondents for whom no end-of-life interview was completed- although it was a finding of some reassurance that no significant differences were found between the two populations of decedents when age of enrolment, gender, level of ID and place of care were examined.

However, the most important limitation of the IDS-TILDA End-of-Life Care study was that the voice of the individual with intellectual disability was not represented directly- instead information is obtained through proxy reporting. The limitations of proxy reporting are recognised, yet proxy reports are frequently used in palliative care research due to the difficulties encountered in research engaging people with a life-limiting illness.[244,245] At the end-of-life, individuals are often too unwell to participate in studies and proxies represent a valuable source of information about the quality and outcomes of care for both the person with life-limiting illness and the respondent.

Finally, it is acknowledged that the timing of the interview and the way that questions are framed may have had an impact on the respondent's proxy response about the deceased. Professional factors such as occupation of formal caregiver respondents, as well as personal factors such as recall biases and grief reactions may also influence responses. As mitigation, care was taken to ensure that a validated survey tool, VOICES-SF, was utilised. Also, use of a population-based sample and fact that interviews took place at differing time periods after death minimised bias.

Implications

Implications for research

The IDS-TILDA End-of-Life Care study has provided an in-depth yet generalisable understanding of the wide range of factors that influence whether people with an intellectual disability can 'live well' with a life-limiting condition and experience a 'good death'. Of primary importance, future research in this area should include direct engagement with people with intellectual disability wherever possible- both those with life-limiting illness and their peers. Input from a broader range of both family members and professional caregivers would also be of value, and it would be helpful to better understand the factors that influence proxy reporting. Data collection from future waves of IDS-TILDA should be utilised to develop understanding of which combinations of services and support are most strongly associated with cost-effectiveness and benefit. This knowledge would serve as an essential prerequisite to the development of interventions that should be studied to determine their efficacy in consistently and effectively enhancing quality of experience and outcomes. Study findings have pointed to areas where the evidence base remains lacking and where further research would be of value in generating insights and understanding relevant to the lived experience of people with intellectual disability and those important to them- they include spirituality, closed communication and the taboo of death and dying, end-of-life decision-making, family and carer support, and death education for peers of people with intellectual disability.

Implications for education

Study findings point to the importance of ensuring that palliative care education and training are embedded as a core part of undergraduate training for all health and social care professionals, and that ongoing continuing professional development is maintained. Education programmes should comprehensively address the distinct characteristics of palliative care need experienced by people with intellectual disability, as described in the typology of palliative care needs. They should ensure that the needs of those important to them (such as family, peers, and staff members) are also recognised and understood. Education and training should focus particularly on communication in order to address the identified issue of closed communication and on challenging the taboo associated with dying and death. Focus should also be given to assisted decision-making and best practice in this area and should acknowledge the importance of heuristics as influencing processes of decision-making. Education should encourage critical appraisal and reflection on the role and respective contributions of general and specialist palliative care staff in care provision in order to support the development of a more mature model of collaboration where staff work at the top of their scope of practice, and where duplication, fragmentation or gaps in service provision are mitigated against.

Implications for policy and practice

The development of a strong and robust body of evidence from this methodologically strong research effort provides a sound basis for the articulation of a best practice model of care for people with an intellectual disability. As previously noted, despite the Report of the National

Advisory Committee on Palliative Care pointing to the need for the specific needs of the population of people with intellectual disabilities to be met, [19] efforts to tailor service provision remain variable and occur at local, rather than national, level. The data described how our current health system operates with respect to the provision of care at the end-of-life to people with intellectual disability and those important to them and provided evidence of areas of strength and weakness. By viewing the needs of people with an intellectual disability through the lens of the Intellectual Disability Palliative Care conceptual framework, it was made apparent that experience and complexity of need are shaped by a variety of factors operating at different levels and interacting in complex ways. The IDS-TILDA End of Life study points to the areas where multifaceted actions can be undertaken at micro-, meso- and exo-and macro-system levels. These actions could include clear guidance on aspects of comprehensive needs assessment that are distinct to the population of people with intellectual disability; sharing and dissemination of strategies that have been successfully employed include people with intellectual disability, their families and peers in communication and care planning and preparation for the end-of-life. The importance of ‘knowing’ the individual underscores the value of GPs and ID service providers developing generalist palliative care capabilities so that they can effectively act as the first line of care provision and points to the importance of adequately resourcing and supporting these individuals to provide care (including consideration of their emotional and bereavement needs). Additionally, actions may include the need for specialist palliative care services to reorganise delivery to safeguard the time to develop effective relationships, and to educate staff to better understand the need for relational continuity and how to better manage communication when relying on proxies. Finally, actions to strengthen or improve collaborative working between specialist and general palliative care services may include interacting on a staged basis with longer periods of time allowed and actively reflecting on practice and team-working.

Appendix 1. Search strategies

Embase Session Results (12 Jun 2022)

No.	Query	Results
#14	((('intellectual disabilities'/exp OR 'intellectual disabilities') OR 'developmental disorder' OR 'mental deficiency' OR 'learning disorder') AND ('palliative therapy' OR 'terminal care' OR 'comfort care' OR 'hospice care' OR hospice)) AND ('case control study'/de OR 'case report'/de OR 'case study'/de OR 'clinical article'/de OR 'clinical study'/de OR 'clinical trial'/de OR 'cohort analysis'/de OR 'comparative study'/de OR 'controlled clinical trial'/de OR 'controlled study'/de OR 'cross sectional study'/de OR 'delphi study'/de OR 'family study'/de OR 'feasibility study'/de OR 'grounded theory'/de OR 'human'/de OR 'human experiment'/de OR 'intervention study'/de OR 'interview'/de OR 'longitudinal study'/de OR 'major clinical study'/de OR 'medical record review'/de OR 'model'/de OR 'multicenter study'/de OR 'outcomes research'/de OR 'pilot study'/de OR 'prospective study'/de OR 'qualitative research'/de OR 'questionnaire'/de OR 'retrospective study'/de OR 'semi structured interview'/de OR 'structured questionnaire'/de) AND ([aged]/lim OR [middle aged]/lim OR [very elderly]/lim OR [young adult]/lim) AND ('article'/it OR 'article in press'/it OR 'letter'/it OR 'short survey'/it) AND [english]/lim	**62**
#13	((('intellectual disabilities'/exp OR 'intellectual disabilities') OR 'developmental disorder' OR 'mental deficiency' OR 'learning disorder') AND ('palliative therapy' OR 'terminal care' OR 'comfort care' OR 'hospice care' OR hospice)) AND ('case control study'/de OR 'case report'/de OR 'case study'/de OR 'clinical article'/de OR 'clinical study'/de OR 'clinical trial'/de OR 'cohort analysis'/de OR 'comparative study'/de OR 'controlled clinical trial'/de OR 'controlled study'/de OR 'cross sectional study'/de OR 'delphi study'/de OR 'family study'/de OR 'feasibility study'/de OR 'grounded theory'/de OR 'human'/de OR 'human experiment'/de OR 'intervention study'/de OR 'interview'/de OR 'longitudinal study'/de OR 'major clinical study'/de OR 'medical record review'/de OR 'model'/de OR 'multicenter study'/de OR 'outcomes research'/de OR 'pilot study'/de OR 'prospective study'/de OR 'qualitative research'/de OR 'questionnaire'/de OR 'retrospective study'/de OR 'semi structured interview'/de OR 'structured questionnaire'/de) AND ([aged]/lim OR [middle aged]/lim OR [very elderly]/lim OR [young adult]/lim) AND ('article'/it OR 'article in press'/it OR 'letter'/it OR 'short survey'/it)	**66**
#12	(('intellectual disabilities'/exp OR 'intellectual disabilities') OR 'developmental disorder' OR 'mental deficiency' OR 'learning disorder') AND ('palliative therapy' OR 'terminal care' OR 'comfort care' OR 'hospice care' OR hospice)	**498**
#11	'palliative therapy' OR 'terminal care' OR 'comfort care' OR 'hospice care' OR hospice	**176934**
#10	hospice	**41450**
#9	'hospice care'	**14325**
#8	'comfort care'	**2250**
#7	'terminal care'	**41071**
#6	'palliative therapy'	**129676**
#5	('intellectual disabilities'/exp OR 'intellectual disabilities') OR 'developmental disorder' OR 'mental deficiency' OR 'learning disorder'	**148681**
#4	'learning disorder'	**34010**
#3	'mental deficiency'	**69706**
#2	'developmental disorder'	**43021**

No.	Query	Results
#1	'intellectual disabilities'/exp OR 'intellectual disabilities'	**9834**

CINAHL plus search

No.	Query	Limiters/ expanders	Results
S1	*(MH "Hospice and Palliative Nursing") OR (MH "Terminal Care (Saba CCC)") OR (MH "Comfort Care (Saba CCC)") OR (MH "Palliative Care") OR (MH "Hospice Care") OR "palliative care OR terminal care OR end-of-life care OR comfort care OR hospice"*	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	50,943
S2	*(MH "Intellectual Disability") OR "intellectual disabilit* OR learning disabilit* OR developmental disabilit* OR mental retard* OR learning dis*" OR (MH "Intellectual Disability, X-Linked")*	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	24,136
S3	S1 AND S2	*Expanders - Apply equivalent subjects* *Search modes - Boolean/Phrase*	160
S4	*S1 AND S2*	*Expanders - Apply equivalent subjects* *Narrow by Language: - English* *Search modes - Boolean/Phrase*	132
S5	*S1 AND S2*	*Expanders - Apply equivalent subjects* *Narrow by SubjectAge: - aged, 80 & over* *Narrow by SubjectAge: - middle aged: 45-64 years* *Narrow by SubjectAge: - aged: 65+ years* *Narrow by SubjectAge: - adult: 19-44 years* *Narrow by SubjectAge: - all adult* *Narrow by Language: - english* *Search modes - Boolean/Phrase*	32

Pubmed

Search no.	Query	Filters	Search Details	Results

27	((((((palliative care) OR (terminal care)) OR (end of life care)) OR (comfort care)) OR (hospice*)) OR (Palliat*)) AND ((((((intellectual disabilit*) OR (learning disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR (learning disorder*))	Case Reports, Classical Article, Clinical Study, Clinical Trial, Comparative Study, Letter, Multicenter Study, Observational Study, Randomized Controlled Trial, English, Adult: 19+ years	(("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]) AND ((("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR (("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]))) AND ((casereports[Filter] OR classicalarticle[Filter] OR clinicalstudy[Filter] OR clinicaltrial[Filter] OR comparativestudy[Filter] OR letter[Filter] OR multicenterstudy[Filter] OR observationalstudy[Filter] OR randomizedcontrolledtrial[Filter]) AND (english[Filter]) AND (alladult[Filter]))	164
26	((((((palliative care) OR (terminal care)) OR (end of	Case Reports, Classical Article, Clinical Study,	(("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal	352

	life care)) OR (comfort care)) OR (hospice*)) OR (Palliat*)) AND ((((((intellectual disabilit*) OR (learning disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR (learning disorder*))	Clinical Trial, Comparative Study, Letter, Multicenter Study, Observational Study, Randomized Controlled Trial, English	care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]) AND ((("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR (("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]))) AND ((casereports[Filter] OR classicalarticle[Filter] OR clinicalstudy[Filter] OR clinicaltrial[Filter] OR comparativestudy[Filter] OR letter[Filter] OR multicenterstudy[Filter] OR observationalstudy[Filter] OR randomizedcontrolledtrial[Filter]) AND (english[Filter]))	
25	((((((palliative care) OR (terminal care)) OR (end of life care)) OR (comfort care)) OR (hospice*)) OR	Case Reports, Classical Article, Clinical Study, Clinical Trial, Comparative Study, Letter,	(("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR	377

	(Palliat*)) AND ((((((intellectual disabilit*) OR (learning disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR (learning disorder*))	Multicenter Study, Observational Study, Randomized Controlled Trial	("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]) AND ((("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR (("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]))) AND (casereports[Filter] OR classicalarticle[Filter] OR clinicalstudy[Filter] OR clinicaltrial[Filter] OR comparativestudy[Filter] OR letter[Filter] OR multicenterstudy[Filter] OR observationalstudy[Filter] OR randomizedcontrolledtrial[Filter])	
24	((((((palliative care) OR (terminal care)) OR (end of life care)) OR (comfort care)) OR (hospice*)) OR (Palliat*)) AND ((((((intellectual disabilit*) OR (learning	Case Reports, Classical Article, Clinical Study, Clinical Trial, Comparative Study, Letter, Multicenter Study, Observational Study	(("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice	377

	disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR (learning disorder*))		care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]) AND ((("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR (("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]))) AND (casereports[Filter] OR classicalarticle[Filter] OR clinicalstudy[Filter] OR clinicaltrial[Filter] OR comparativestudy[Filter] OR letter[Filter] OR multicenterstudy[Filter] OR observationalstudy[Filter])	
23	((((((palliative care) OR (terminal care)) OR (end of life care)) OR (comfort care)) OR (hospice*)) OR (Palliat*)) AND ((((((intellectual disabilit*) OR (learning disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR	Case Reports, Classical Article, Clinical Study, Clinical Trial, Comparative Study, Letter, Multicenter Study	(("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields]	377

	(learning disorder*))		AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]) AND ((("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR (("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]))) AND (casereports[Filter] OR classicalarticle[Filter] OR clinicalstudy[Filter] OR clinicaltrial[Filter] OR comparativestudy[Filter] OR letter[Filter] OR multicenterstudy[Filter])	
21	((((((palliative care) OR (terminal care)) OR (end of life care)) OR (comfort care)) OR (hospice*)) OR (Palliat*)) AND ((((((intellectual disabilit*) OR (learning disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR (learning disorder*))	Case Reports, Classical Article, Clinical Study, Clinical Trial, Comparative Study, Letter	(("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]) AND ((("intellectual"[All Fields] OR "intellectualism"[All Fields] OR	353

			"intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR (("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]))) AND (casereports[Filter] OR classicalarticle[Filter] OR clinicalstudy[Filter] OR clinicaltrial[Filter] OR comparativestudy[Filter] OR letter[Filter])	
22	((((((palliative care) OR (terminal care)) OR (end of life care)) OR (comfort care)) OR (hospice*)) OR (Palliat*)) AND ((((((intellectual disabilit*) OR (learning disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR (learning disorder*))	Case Reports, Classical Article, Clinical Study, Clinical Trial, Comparative Study, Letter, Meta-Analysis	(("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]) AND ((("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR	366

			(("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]))) AND (casereports[Filter] OR classicalarticle[Filter] OR clinicalstudy[Filter] OR clinicaltrial[Filter] OR comparativestudy[Filter] OR letter[Filter] OR meta-analysis[Filter])	
20	((((((palliative care) OR (terminal care)) OR (end of life care)) OR (comfort care)) OR (hospice*)) OR (Palliat*)) AND ((((((intellectual disabilit*) OR (learning disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR (learning disorder*))	Case Reports, Classical Article, Clinical Study, Clinical Trial, Comparative Study	(("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]) AND ((("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR (("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All	333

			Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]))) AND (casereports[Filter] OR classicalarticle[Filter] OR clinicalstudy[Filter] OR clinicaltrial[Filter] OR comparativestudy[Filter])	
19	((((((palliative care) OR (terminal care)) OR (end of life care)) OR (comfort care)) OR (hospice*)) OR (Palliat*)) AND ((((((intellectual disabilit*) OR (learning disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR (learning disorder*))	Case Reports, Classical Article, Clinical Study, Clinical Trial	(("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]) AND ((("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR (("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All	295

			Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]))) AND (casereports[Filter] OR classicalarticle[Filter] OR clinicalstudy[Filter] OR clinicaltrial[Filter])	
18	((((((palliative care) OR (terminal care)) OR (end of life care)) OR (comfort care)) OR (hospice*)) OR (Palliat*)) AND ((((((intellectual disabilit*) OR (learning disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR (learning disorder*))	Case Reports, Classical Article, Clinical Study	(("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]) AND ((("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR (("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]))) AND (casereports[Filter] OR classicalarticle[Filter] OR clinicalstudy[Filter])	295

17	((((((palliative care) OR (terminal care)) OR (end of life care)) OR (comfort care)) OR (hospice*)) OR (Palliat*)) AND ((((((intellectual disabilit*) OR (learning disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR (learning disorder*))	Case Reports, Classical Article	(("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]) AND ((("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR (("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]))) AND (casereports[Filter] OR classicalarticle[Filter])	202
16	((((((palliative care) OR (terminal care)) OR (end of life care)) OR (comfort care)) OR (hospice*)) OR (Palliat*)) AND ((((((intellectual disabilit*) OR	Case Reports	(("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR	202

	(learning disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR (learning disorder*))		"end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]) AND ((("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR (("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]))) AND (casereports[Filter])	
15	((((((palliative care) OR (terminal care)) OR (end of life care)) OR (comfort care)) OR (hospice*)) OR (Palliat*)) AND ((((((intellectual disabilit*) OR (learning disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR (learning disorder*))		("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All	1,723

			Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]) AND ((("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR (("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]))	
14	(((((intellectual disabilit*) OR (learning disabilit*)) OR (developmental disabilit*)) OR (mental retard*)) OR (idiocy)) OR (learning disorder*)		(("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]) OR (("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]) OR (("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]) OR ("idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]) OR (("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields])	294,502

13	learning disorder*		("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disorder*"[All Fields]	127,486
12	idiocy		"idiocies"[All Fields] OR "intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields] OR "idiocy"[All Fields]	112,955
11	mental retard*		("mental"[All Fields] OR "mentalities"[All Fields] OR "mentality"[All Fields] OR "mentalization"[MeSH Terms] OR "mentalization"[All Fields] OR "mentalizing"[All Fields] OR "mentalize"[All Fields] OR "mentalized"[All Fields] OR "mentally"[All Fields]) AND "retard*"[All Fields]	42,106
10	developmental disabilit*		("developmental"[All Fields] OR "developmentally"[All Fields]) AND "disabilit*"[All Fields]	43,490
9	learning disabilit*		("learning"[MeSH Terms] OR "learning"[All Fields] OR "learn"[All Fields] OR "learned"[All Fields] OR "learning s"[All Fields] OR "learnings"[All Fields] OR "learns"[All Fields]) AND "disabilit*"[All Fields]	36,093
8	intellectual disabilit*		("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*"[All Fields]	73,718
7	(((((palliative care) OR (terminal care)) OR (end of life care)) OR (comfort care)) OR (hospice*)) OR (Palliat*)		"palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]) OR ("terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])) OR ("patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]) OR "hospice*"[All Fields] OR "palliat*"[All Fields]	235,657
6	Palliat*		"palliat*"[All Fields]	137,107
5	hospice*		"hospice*"[All Fields]	36,895

4	comfort care		"patient comfort"[MeSH Terms] OR ("patient"[All Fields] AND "comfort"[All Fields]) OR "patient comfort"[All Fields] OR ("comfort"[All Fields] AND "care"[All Fields]) OR "comfort care"[All Fields]	22,157
3	end of life care		"terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])	97,512
2	terminal care		"terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]	66,303
1	palliative care		"palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields]	93,735

Cochrane

0 Cochrane Reviews matching palliative care in All Text AND intellectual disability in Title Abstract Keyword - in Trials (Word variations have been searched)

Appendix 2. End-of-life Study Survey Instrument.

A convergent parallel mixed methods study of the end-of-life care experiences of people with intellectual disability in Ireland: Lessons learned from IDS TILDA.

Trinity
College
Dublin
The University of Dublin

AIIHPC
All Ireland Institute of
Hospice and Palliative Care

Dear Carer,

Thank you for taking the time to be involved in this very important study. People with intellectual disability are known to die at a much earlier age than the general population and can have more complex end-of-life needs. However little is known about this time in their lives. By completing this study you will contribute to building a picture of what end-of-life is for people with intellectual disability and improving the life experiences and end-of-life experiences for people with intellectual disability through policy and practice influence.

This interview is about the care and services received by you and your friend/relative in the last months of his/her life. The information you give will help us improve care for people with an intellectual disability who are dying, and for their family, friends and carers. Your views are, therefore, important to us.

We realise this interview may bring back strong memories. If you feel upset or distressed, you do not have to continue and can stop at any time. We are interested in finding out the experiences of all people who have died whether suddenly, after a short illness, or after a long illness. We also think it is important to find out about the care you and the family received at the time of death and in the months since then. Some of the questions may not be relevant to you. Please complete as much of the interview as you can.

Your answers to these questions will be treated as strictly confidential. No names will be used in the reports we write.

If you would rather not answer one of the questions, please continue with the next one. You are free to end the interview at any time.

We are very interested in what you have to say. Please elaborate if necessary.

Many thanks and kind regards,

Prof. Mary McCarron.

Prof. Mary McCarron

INFORMATION ABOUT YOU BOTH

Q1 **What was your relationship to him/her? Were you his/her:**

Tick one only	
Parent	
Other relative	
Friend	
Neighbour	
Husband/Wife/Partner	
Son/Daughter	
Brother/Sister	
Son-in- law/Daughter-in-law	
ID service staff in usual home	
Keyworker	
Staff in broader ID service (e.g., day service, supported employment, home support, etc.)	
Please specify role:	
Warden (sheltered accommodation)	
Other official	
Someone else	

Q2 **How long did you know the deceased?**

Q3 **What was his/her age when (s)he died?**

Q4

Was it a sudden death?

Yes	
No	

Q5

Where was his/her usual home?

At home with both parents	
At home with one parent	
At home with sibling	
At home with other relative	
Foster care and boarding-out arrangements	
Living independently	
Living semi-independently	
5-day community group home	
7-day (48-week) community group home (goes home for holidays)	
7-day (52-week) community group home	
5-day residential centre	
7-day (48-week) residential centre (goes home for holidays)	
7-day (52 week) residential centre	
Nursing/care home	
Mental health community residence	
Psychiatric hospital	
Intensive placement (challenging behaviour)	
Intensive placement (profound or multi-disability)	
Other (please specify):	

Q5 contd.	

Q5. (a) Did this change over his/her last year of life?

Yes	
No	
Don’t know	
If yes, please describe:	

Q5. (b) If yes, why did this change?

Increased healthcare support needs	
Change in family circumstances	
Decreased access to resources	
Staffing numbers/expertise	
Other:	
If yes, please describe:	

Q6 **What other locations apart from usual home did he/she reside in over his/her final year of life?**

Please tick all as appropriate:	When did this change take place?	How long approx. did he/she stay here?
At home with both parents		
At home with one parent		
At home with sibling		
At home with other relative		
Foster care and boarding-out arrangements		
Living independently		
Living semi-independently		
5-day community group home		
7-day (48-week) community group home (goes home for holidays)		
7-day (52-week) community group home		
5-day residential centre		
7-day (48-week) residential centre (goes home for holidays)		
7-day (52 week) residential centre		
Nursing/care home		
Mental health community residence		
Psychiatric hospital		
Intensive placement (challenging behaviour)		
Intensive placement (profound or multi-disability)		
Hospice		
Acute hospital		
Specialist unit within ID service		
Other (please specify):		

Q7

How long had (s)he been ill before (s)he died?

Tick one only	
(S)he was not ill – (s)he died suddenly and unexpectedly	
Less than 24 hours	
One day or more, but less than one week	
One week or more, but less than one month	
One month or more, but less than six months	
Six months or more, but less than one year	
One year or more	

Q7 (a) If (s)he was unwell for more than one month was an advanced care plan put in place?

Yes	
No	

Q8

What was the cause of death and what were the contributing causes as listed on the death certificate?

Q9

Did (s)he spend any time at his/her usual home during the last three months of life?

Tick one only	
Yes – **go to Q10**	
(S)he was in a nursing/care home for the whole 3 months – **go to Q22**	
No – **go to Q33**	

Q10 **When (s)he was at his/her usual home, or living within an ID service setting, in the last three months of life, did (s)he get any help from any of the services listed below?**

These may be provided by different organisations, such as voluntary organisations, a private agency or social services.

Tick all that apply	*General community based services*	*ID Service based*
Community or public health nurse (a nurse who came to his/her usual home from a community primary care team)		
A member of the community palliative care team (often known as home care nurse or hospice nurse)		
Irish Cancer Society/Irish Hospice Foundation Night Nurse (someone who comes to the house for a few hours or overnight to care for the patient)		
Intellectual Disability Service nurse from multidisciplinary team		
Any other nurse (describe):		
ID service keyworker		
ID service support worker		
ID service health care assistant		
Home care worker, home care aide or home help		
Social worker		
Psychologist		
Counsellor		
Religious leader such as priest, rabbi, pastor, imam etc.		
Meals-on-wheels or other home delivered meals		
Hospice Care		
Occupational therapist (OT)		
Physiotherapist		
Speech and Language Therapist		
Dietician		
Community intervention team (a team of nurses and home care workers who provide care over the short term to allow someone to remain at home and prevent hospital admission)		
(S)he did not receive any care		
Don’t know		
Something else please write in the space below:		

If (s)he died suddenly with no illness or time for care, **please go to Q47**.

Q11 **When (s)he was at his/her usual home, or living within an ID service setting, in the last three months of life, did all these services work well together?**

Yes, definitely	
Yes, to some extent	
<u>If Yes:</u> Can you tell us in what way did they work well together?	
No, they did not work well together	
<u>If No:</u> Can you tell us in what way did they not work well together?	
(S)he did not receive any care	
Don't know	

Q11a **If you had hospice care, thinking specifically about this, how well did the hospice services work with the intellectual disability services?**

Q12 **Overall, do you feel that you and your family <u>OR</u> staff team got as much help and support from health and social services as you needed when caring for him/her?**

Services:	ID	*Hospice*	*General health*
Yes, we got as much support as we wanted			
Yes, we got some support but not as much as we wanted			
<u>If Yes:</u> What was particularly helpful?			
No, although we tried to get more help			
No, but we did not ask for more help			
<u>If No:</u> What was particularly unhelpful?			
We did not need help			

Q13 **Do you think his/her illness had an effect on other residents in the house?**

Yes, <u>it did have an effect</u>	
No, <u>it did not have an effect</u>	
<u>If Yes:</u> Do you think the residents got the help and support they needed during this time? What kind of help and support did they receive?	

PAIN CONTROL

Q14

Did you use any type of assessment tool to assess pain?

Disability Distress Assessment Tool (DisDAT)	
Other:	
No	

Q15

How did he/she express his/her pain?

Verbally	
Facial Expressions	
Body Language	
Other:	

Q16

During the last three months of his/her life, while (s)he was at his/her usual home, how well was his/her pain relieved?

Tick one only	
Does not apply – (s)he did not have any pain	
Completely, all of the time	
Completely, some of the time	
Partially	
Not at all	
Don’t know	
Please tell us what did or did not help with pain control:	

URGENT CARE PROVIDED OUT OF HOURS

Q17 **In the last three months of life, while he/she was at his/her usual home, or living within an ID service setting, did he/she ever need to contact a health professional for something urgent in the evening or at the weekend?**

Tick one only	
Not at all in the last 3 months – **go to Q22**	
Once or twice – **go to Q18**	
Three or four times – **go to Q18**	
Five times or more – **go to Q18**	
Don’t know – **go to Q22**	

Q18 **The last time this happened, who did (s)he contact, or who was contacted on his/her behalf?**

Tick all that apply	
His/her GP or the out-of-hours number	
A Swiftcare clinic or equivalent	
Community or public health nurse	
(S)he used his/her ‘lifeline’ portable personal pendant	
An ambulance	
An ID service multidisciplinary team member on call	
An on-site ID service multidisciplinary team member (e.g. RNID)	
A hospice	
Something else – please write in the space below:	

Q19 **What happened as a result? Was (s)he...**

Tick one only	
Tended to by an on-site ID service multidisciplinary team member (e.g., RNID)	
Visited by an ID service multidisciplinary team member (e.g., RNID) at usual home or ID service residential setting that was not usual home	
Visited by his GP at usual home or ID service residential setting that was not usual home	
Visited by another GP at usual home or ID service residential setting that was not usual home	
Visited by a nurse at usual home or ID service residential setting that was not usual home	
Visited by a hospice doctor at usual home or ID service residential setting that was not usual home	
Given medical advice over the telephone	
Given another number to ring to get medical advice	
Advised to go to an out-of-hours GP surgery	
Advised to go to the GP surgery when it opened	
Advised to go to an Accident and Emergency Department at a hospital	
Advised to call 999	
Something else – please write in the space below:	

Q20 **In your opinion, was this the right thing for them to do, or not?**

Tick one only	
Yes	
No	
Not sure	

Q21 **Overall, do you feel that the care (s)he got when (s)he needed care urgently in the evenings or weekends in the last three months of life was:**

Tick one only	
Excellent	
Good	
Fair	
Poor	
Don’t know	

COMMUNITY AND PUBLIC HEALTH NURSES

If (s)he had care in the last 3 months from community and public health nurses, **go to Q22**. If (s)he did not, **go to Q24.**
(Community Nurse includes Palliative Care Nurse)

Q22 **How often did the community and public health nurses visit (at the most frequent time)?**

Tick one only	
More than once a day	
Every day	
2-6 times a week	
Once a week	
2-3 times a month	
Less often	
Don't know	

Q23 **Overall, do you feel that the care (s)he got from the community and public health nurses in the last three months of life was:**

Tick one only	
Excellent	
Good	
Fair	
Poor	
Don't know	

CARE FROM THE GP

Q24 **In the last 3 months, did (s)he see a GP?**

Tick one only		
Yes		
Was this his/her preferred GP?	Yes ☐	No ☐
(S)he did not have a preferred GP		
(S)he did not need to see a GP – **go to Q29**		
Don't know– **go to Q29**		

Q25 **How much of the time was (s)he treated with respect and dignity by the GPs?**

Tick one only	
Always	
Most of the time	
Some of the time	
Never	
Don't know	

Q26 **Were you able to discuss any worries and fears you may have had about his/her condition, treatment or tests with the GPs?**

Tick one only	
I had no worries or fears to discuss	
Yes, I discussed them as much as I wanted	
Yes, I discussed them, but not as much as I wanted	
No, although I tried to discuss them	
No, but I did not try to discuss them	

Q27 **Overall, if the GP visited him/her at home in the last three months, how easy or difficult was it to get him/her to visit?**

Tick one only	
Very easy	
Fairly easy	
Fairly difficult	
Very difficult	
Don’t know	
(S)he wanted the GPs to visit but they would not visit	
Does not apply – the GP did not need to visit	
Don’t know	

Q28 **Overall, do you feel that the care (s)he got from the GP in the last three months of life was:**

Tick one only	
Excellent	
Good	
Fair	
Poor	
Don’t know	
Please feel free to make comments in the space below:	

NURSING/CARE HOMES

Q29 **Did he/she live or stay in a care home at any time during his/her last three months of life?**

Tick one only	
Yes, (s)he was in a nursing/care home	
Please write the name of the nursing/care home:	
No – **go to Q33**	
Don’t know – **go to Q33**	

Q30 **How much of the time was (s)he treated with respect and dignity by the staff at the nursing/care home?**

Tick one only	
Always	
Most of the time	
Some of the time	
Never	
Don’t know	

Q31 **During the last three months of his/her life, while (s)he was in the nursing/care home, how well was his/her pain relieved?**

Tick one only	
Does not apply – (s)he did not have any pain	
Completely, all of the time	
Completely, some of the time	
Partially	
Not at all	
Don’t know	

Q32 **Overall, do you feel that the care (s)he got from the nursing/care home in the last three months of life was:**

Tick one only	
Excellent	
Good	
Fair	
Poor	
Don't know	

HOSPITAL CARE

Q33 **Did (s)he stay in hospital at any time during his/her last three months of life?**

Tick one only	
Yes	
Please write the name of the last hospital (s)he stayed in:	
No – **go to Q38**	
Don't know – **go to Q38**	

Q34 **During his/her last hospital admission, how much of his/her time was (s)he treated with respect and dignity by the hospital doctors and nurses?**

Please answer for both doctors and nurses

	Doctors	Nurses
Always		
Most of the time		
Some of the time		
Never		
Don't know		

Q35 **During this last hospital admission, how well was his/her pain relieved?**

Tick one only	
Does not apply – (s)he did not have any pain	
Completely, all of the time	
Completely, some of the time	
Partially	
Not at all	
Don’t know	

Q36 **Did the hospital services work well together with his/her GP, ID services and other services outside of the hospital?**

Tick one only	
Yes, definitely	
Yes, to some extent	
No, they did not work well together	
Don’t know	

Q37 **Overall, do you feel that the care (s)he got from the staff in the hospital on that admission was:**
Please answer for both doctors and nurses

	Doctors	Nurses
Excellent		
Good		
Fair		
Poor		
Don’t know		

LAST HOSPICE ADMISSION

Q38 **Did (s)he stay in a hospice at any time during his/her last three months of life?**

Tick one only	
Yes	
The name of the last hospice:	
No – **go to Q43**	
Don't know – **go to Q43**	

Q39 **How much of the time was (s)he treated with respect and dignity by the hospice doctors and nurses?**

Please answer for both doctors and nurses

	Doctors	Nurses
Always		
Most of the time		
Some of the time		
Never		
Don't know		

Q40 **During the last three months of his/her life, while (s)he was in the hospice, how well was his/her pain relieved?**

Tick one only	
Does not apply – (s)he did not have any pain	
Completely, all of the time	
Completely, some of the time	
Partially	
Not at all	
Don't know	

Q41 **Overall, do you feel that the care (s)he got from the staff in the hospice was:**

Tick one only	
Excellent	
Good	
Fair	
Poor	
Don’t know	

Q42 **In general, how well did the mainstream services (all services mentioned above other than the ID services) meet the needs of the decedent?**

CHANGE IN RESIDENCE TO OR WITHIN ID SERVICES

Q43 **Did (s)he stay in a unit/placement within ID services that was not his/her usual home at any time during his/her last three months of life?**

Tick one only	
Yes	
No – **go to Q47**	
Don't know – **go to Q47**	

Q44 **How much of the time was (s)he treated with respect and dignity by the staff there?**

Tick one only	
Always	
Most of the time	
Some of the time	
Never	
Don't know	

Q45 **During the last three months of his/her life, while (s)he was in this unit/residential placement, how well was his/her pain relieved?**

Tick one only	
Does not apply – (s)he did not have any pain	
Completely, all of the time	
Completely, some of the time	
Partially	
Not at all	
Don’t know	

Q46 **Overall, do you feel that the care (s)he got from the staff in the unit/residential placement was:**

Tick one only	
Excellent	
Good	
Fair	
Poor	
Don’t know	

EXPERIENCES IN THE LAST TWO DAYS OF LIFE

Q47 **During his last two days of life was (s)he:**

Tick one only	
At usual home all the time	
In a nursing/care home all the time	
In a hospital all the time	
In a hospice all the time	
In a residential setting within the ID service that was not his/her usual home	
Other	

Q48 **How much of the time was (s)he treated with respect and dignity in the last two days of life?**

Please answer for both doctors and nurses

	Doctors	Nurses
Always		
Most of the time		
Some of the time		
Never		
Don't know		

Q49

Please look at the following statements and tick the answer box that corresponds most with your opinion about the help (s)he received in the last two days of life

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree Strongly	Disagree	Does Not Apply	Don’t Know
There was enough help available to meet his/her personal care needs (such as toileting)							
There was enough help with nursing care, such as giving medicine and helping him/her find a comfortable position in bed							
The bed area and surrounding environment had adequate privacy for him/her							

Q50 **During the last two days, how would you assess the overall level of support that was given in the following areas from those caring for him/her?**

	Excellent	Good	Fair	Poor	Not Applicable	Don't Know
Relief of Pain						
Relief of Symptoms other than Pain						
Spiritual Support						
Emotional Support						
Support to Stay where s(h)e wanted to be						

CIRCUMSTANCES SURROUNDING HIS/HER DEATH

Q51 **Did (s)he know (s)he was likely to die?**

Yes, certainly	
Yes, probably	
<u>If Yes</u>: Was (s)he told (s)he was likely to die or did (s)he come to the realisation herself/himself?	
Probably not	
No, definitely	
Died Suddenly	
Not sure	

Q52

In your opinion, did the person who told him/her (s)he was likely to die break the news in a sensitive way?

Tick one only	
Yes, definitely	
Yes, to some extent	
No, not at all	
Don’t know	
Does not apply – they did not know (s)he was dying	
Does not apply – they did not tell him/her (s)he was dying	

Q52 a

Was it told in the appropriate manner with the appropriate accessible tools to meet their communication needs?

Tick one only	
Yes	
No	
Please tell us:	

Q52 b

Do you think it was the right thing to tell him/her or not?

Yes, certainly	
Yes, probably	
Probably not	
No, definitely	
Died Suddenly	
Not sure	
Does not apply – they did not tell him/her (s)he was dying	

Q53

Were you contacted soon enough to give you time to be with him/her before (s)he died?

Tick one only	
Yes	
No	
I was there already	
It was not clear that (s)he was going to die soon	
I couldn’t have got there anyway	

Q54

Who was present at time of death?

Q55

Where did (s)he die?

Tick one only	
In his/her usual home	
In his/her family home (if not usual home)	
In the home of another family member or friend	
In a hospital ward	
Name of the hospital:	
In a hospital Accident and Emergency Department	
In a hospital Intensive Care Unit	
Name of the hospital:	
In a hospice	
Name of the hospice:	
In a nursing/care home	
Name of the nursing/care home:	
In a residential setting within the ID service that was not his/her usual home	
Name of unit/setting:	
In an ambulance on the way to hospital/hospice	
Somewhere else:	

Q56 **Did (s)he ever say where (s)he would like to die?**

Tick one only	
Yes – **go to Q57**	
No – **go to Q59**	
Not sure – **go to Q59**	

Q57 **Where did (s)he say that (s)he would like to die?**

Tick one only	
In usual home	
In family home (if not usual home)	
In a hospice	
In a hospital	
In a nursing/care home	
(S)he said (s)he did not mind where (s)he died	
(S)he changed his/her mind about where (s)he wanted to die	
Somewhere else:	

Q58 **Did the health care staff OR ID service support staff have a record of this?**

Tick one only	
Yes	
No	
Not sure	

Q59 **Do you think (s)he had enough choice about where (s)he died?**

Tick one only	
Yes	
No	
Not sure	
(S)he died suddenly	

Q60 **On balance, do you think that (s)he died in the right place?**

Tick one only	
Yes	
No	
Not sure	

FAMILY AND FRIENDS

Q61 **Were you or his/her family given enough help and support by any healthcare professionals involved in providing care (e.g. GP, nurses, healthcare assistants) at the actual time of his/her death?**

Tick one only	
Yes, definitely	
Yes, to some extent	
No, not at all	
Don’t know	

Q62 **After (s)he died, did the healthcare professionals involved in providing care at that time (e.g. GP, nurses, healthcare assistants) deal with you or his/her family in a sensitive manner?**

Tick one only	
Yes	
No	
Don’t know	
Does not apply, I didn’t have any contact with the staff	
Please feel free to make comments in the space below:	

FAMILY AND FRIENDS/ID SERVICE SUPPORT STAFF

Q63 **Were you and/or his/her family given enough help and support by the ID service and other support staff at the actual time of his/her death?**

Tick one only	
Yes, definitely	
Yes, to some extent	
No, not at all	
Don’t know	

Q64 **Looking back over the last three months of his/her life, was (s)he involved in decisions about his/her care?**

Tick one only	
Yes, Definitely	
Yes, to some extent	
No, not at all	
Don’t know	

If no, what were the reasons (s)he was not involved?

Q65 **Looking back over the last three months of his/her life, were you involved in decisions about his/her care as much as you would have wanted?**

Tick one only	
I was involved as much as I wanted to be	
I would have liked to be more involved	
I would have liked to be less involved	
Don’t know	

Q66	**Did (s)he have an end-of-life care plan?**

Tick one only	
Yes	
No	
Name of Plan:	

Q67	**Were any decisions made about his/her care that (s)he would not have wanted?**

Tick one only	
Yes	
No	
Don’t know	

Please describe:

Q68	**Overall, and taking all services into account, how would you rate his/her care in the last three months of life?**

Tick one only	
Excellent	
Very Good	
Good	
Fair	
Poor	
Don't know	

Q69	**Since (s)he died, have you talked to anyone from health and social services, the Intellectual Disability Service or from a bereavement service, about your feelings about his/her illness and death?**

Tick one only	
Yes	
No, not available	
Available but didn't want to avail of it	

Q70	**Did the other residents in the house receive bereavement support?**

Tick one only	
Yes	
No, not available	
Available but didn't want to avail of it	
Support received from:	

POST DEATH/FUNERAL RITUALS

Q71 **What is the normal funeral ritual?**

Please describe:

Q72 **Who was involved in arranging the funeral service?**

Please describe:

Q73 **Who was at the funeral service?**

Family	
Friends	
Staff from ID Service	
Other, please specify:	

Q74 **Who decided where the person would be buried?**

Please describe:

Q75	**Where was the person laid to rest?** Family Plot Service Plot Private Plot Location:
Q76	**How soon after the person died did another person take their bed/room?** Please describe:

HEALTH STATUS: PHYSICAL HEALTH

Q77 **Since we last talked to him/her, did a doctor ever tell him/her that (s)he had any of these conditions?**

Condition	***Type***
Heart Disease	
Endocrine Disease	
Eye Disease	
Hypertension	
Joint Disease	
Lung Disease	
Gastrointestinal Disease	
Liver Disease	
Cancer	
Stroke	
Neurological Disease	
Mental Health Problems	

OTHER MAJOR ILLNESSES

Q78 **Did (s)he have any (other) major illnesses since the last interview/in the two years preceding his/her death?**

Tick one that applies	
Yes	
No	
Don't know	

What illness was that?

Or tick if unknown : ☐

MENTAL HEALTH

Q79	**I would now like to ask you a few questions about his/her mood during the last year of his/her life.**

Do you think (s)he was depressed during his/her last year of life?	
No	
IF YES: Was (s)he depressed sometimes or frequently?	
Yes, sometimes	
Yes, frequently	
Don't know	

Q80	**How often do you think (s)he felt happy during his/her last year of life?**

Please tick one that applies	
Often	
Sometimes	
Rarely	
Never	
Don't know	

Q81	**And how about the last three months of his/her life, how often do you think (s)he felt contented or at peace during this time?**

Please tick one that applies	
Often	
Sometimes	
Rarely	
Never	
Don't know	

CARE RECEIVED

Q82	**Please use the space below if there is anything more you would like to say about the care provided:**

CARER'S INFORMATION

Q83 **Are you:**

Male	
Female	

Q84 **What is your age?**

Q85 **How would you describe your own health?**

Excellent	
Very Good	
Good	
Fair	
Poor	

Thank you most sincerely for your time

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