

Placing the Preferences of People with Profound Intellectual and Multiple Disabilities At the Center of End-of-Life Decision Making Through Storytelling

Research and Practice for Persons
with Severe Disabilities
2019, Vol. 44(4) 267–279
© The Author(s) 2019



Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1540796919879701
rpsd.sagepub.com



Joanne Watson¹ , Hille Voss², and Melissa J. Bloomer¹

Abstract

With a focus on the use of narrative approaches, this article is a commentary on decision-making support for people with profound intellectual and multiple disability (PIMD) at the end-of-life. Due to improved health care, people with PIMD are living longer lives than ever before. Therefore, they are increasingly facing decisions relating to end-of-life care and planning. Despite the increased attention that has been given to end-of-life planning, opportunities to have preferences responded to at the end-of-life are more likely afforded to people considered to have cognitive and decision-making capacity. Those supporting people with PIMD to plan for and make decisions about end-of-life care face several challenges. These challenges are rooted in difficulties with communication exchange between people with PIMD and their communication partners, leading to a widely held perception of decision-making incompetence for this population. In response to this challenge, this article draws on empirical research to discuss decision-making support within the context of palliative care and advance care planning, specifically for people with PIMD. It promotes decision-making support as an approach to assist supporters of people with PIMD to allow those people's expressions of preferences to be acknowledged and acted upon at the end-of-life. The use of narrative is presented and discussed as a tool for enabling this responsiveness, specifically within the context of end-of-life planning.

Keywords

end-of-life, profound intellectual and multiple disabilities, supported decision making, palliative care, storytelling

People with profound intellectual and multiple disability (PIMD) have relatively higher incidents of life-threatening medical conditions (e.g., aspirational pneumonia, dysphagia, and respiratory disorders), which have historically resulted in them dying earlier than their family carers. Although it is a positive evolution that people with PIMD are living longer lives, it means that they are now frequently outliving their family carers, resulting in a greater occurrence of them dying with the support of palliative care services (Heslop et al., 2014). This creates a challenge for those providing support within the context of palliative care and end-of-life decision making for people with PIMD, who traditionally have not had access to such services. These challenges are rooted in difficulties with communication exchange between people with PIMD and

¹Deakin University, Geelong, Victoria, Australia

²Netherlands Institute for Health Services Research (NIVEL), Utrecht, The Netherlands

Corresponding Author:

Joanne Watson, 221 Burwood Hwy, Burwood VIC Deakin University, Burwood, Victoria, Australia 3125.

Email: joanne.watson@deakin.edu.au

their communication partners. These difficulties lead to a widely held perception of decision-making incompetence for this population.

This article discusses advance care planning and end-of-life decision-making within the complex support relationships between people with PIMD and those who know, love, and support them. The authors draw on the strengthening paradigm shift created by Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2008), establishing a strong legislative and moral base from which to develop mechanisms for supporting autonomy for all citizens, including at the end-of-life. The authors discuss the specific challenges faced by people with PIMD and their supporters in achieving autonomy, particularly within the context of end-of-life care. The authors respond to these challenges by drawing on empirical research to discuss the use of a narrative-based methodology for supporting decision-making within the context of palliative care and advance care planning, specifically for people with PIMD.

Advance Care Planning and End-of-Life Care

A person's opportunity to express their autonomy at the end of life has been linked to a death that meets the psychological, spiritual, physical, and social needs of the person who is dying (Detering, Hancock, Reade, & Silvester, 2010; Granda-Cameron & Houldin, 2012). Advance care planning is designed to aid people to consider and communicate their future treatment preferences in the context of their own goals and values, including for end-of-life care (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2015; Sudore et al., 2017). With provision to include value statements and treatment preferences to guide decision-makers involved in care, and/or instructional directives that explicitly detail consent and refusal for specific treatments (Advance Care Planning Australia, 2018), advance care plans are designed to honor a person's preferences and guide substitute and supported decision-makers, particularly at the end-of-life.

Despite the importance of ensuring end-of-life care wishes and preferences are known and communicated, there is widespread reluctance among individuals, family, and health professionals to talk about end-of-life treatment preferences, dying, death, and associated existential concerns (Bloomer et al., 2018; Brazil et al., 2017; George et al., 2016). Even when it is evident that death is inevitable, health professionals report significant challenges in communicating about dying and discussing end-of-life care preferences with patients and others (Bloomer et al., 2018; Bloomer, Lee, & O'Connor, 2011; George et al., 2016). When a person's capacity to contribute to discussions is questioned, as it may be for people with PIMD, challenges in communication between caregivers, surrogates, and supported decision-makers about care decisions may arise (Bloomer, Digby, Tan, Crawford, & Williams, 2016; Bloomer & Digby, 2012; Quinn, Gur, & Watson, 2018). In the absence of effective communication and when a person's preferences are not known, end-of-life care may be suboptimal (Bloomer et al., 2019b; Visser et al., 2014), with the dying person likely to receive a more "generic" plan of care. Moreover, when people are given opportunities to discuss their wishes and preferences, the quality of their end-of-life care is enhanced (Detering et al., 2010).

In 2015, the ACSQHC recognized the importance of addressing the provision of end-of-life care in hospitals, correlating with increased empirical focus on end-of-life communication and planning in Australia and internationally (Anderson, Bloch, Armstrong, Stone, & Low, 2019; Turner & Flemming, 2019). Other research has examined the needs and care provision for highly vulnerable groups, such as older people (Bloomer et al., 2018; Bloomer et al., 2019b; Witham & Hockley, 2016) and those from culturally and linguistically diverse backgrounds (Bloomer et al., 2019a; Johnstone, Hutchinson, Redley, & Rawson, 2015). Yet, little attention has been paid to such planning in the lives of people with intellectual disability, including people with PIMD. This is despite the life expectancy of people with intellectual disability increasing similarly to the general population (Coppus, 2013). Where the needs of people with intellectual disability have been considered, the focus is on those with mild intellectual disability, leaving people with PIMD at most risk of not being involved in end-of-life decisions (Bekkema, de Veer, Wagemans, Hertogh, & Francke, 2014; Kirkendall, Linton, & Farris, 2017; Stancliffe, Wiese, & Read, 2017; Voss et al., 2019). Bekkema et al. (2014) reported that while people with severe intellectual disability had their end-of-life preferences taken into account only 2.9% of the time, people with mild or moderate intellectual disability had their

preferences taken into account 27.8% of the time. This is despite relatively higher incidence among people with severe intellectual disability of medical conditions (e.g., aspiration pneumonia, respiratory disorders and dysphagia) that require critical decision-making relating to end-of-life care. Only recently has attention been paid to the preferences of people with PIMD within end-of-life planning and decision-making (Watson, Wilson, & Hagiliassis, 2017; Young, Hogg, & Garrard, 2017; Zaal-Schuller, Willems, Ewals, van Goudoever, & de Vos, 2016).

The Creation of a New Paradigm for Supporting Autonomy for People with Disability

The United Nations' General Assembly adopted the CRPD on December 13, 2006, and it was implemented in May 2008 (United Nations, 2008). The CRPD was the first international human rights treaty to specifically recognize that people with intellectual disability have a right to autonomy. This Convention has served as a catalyst for reconsidering notions of decision-making support for people with intellectual disability, in all aspects of life. Article 12 of the Convention challenges all Nations' use of substitute decision making. Substitute decision making involves the formal (legal) or informal appointment of a person to make decisions on behalf of another considered to lack decision-making capacity (Watson, 2016a). Decisions made under a substitute decision-making model are generally based on an objective assessment of the "best interests" of the person concerned. Article 12 of the Convention not only challenges the notion of decision-making incapacity, and the use of substitute decision making, but also the notion of best interest, which sits at the core of substitute decision-making practice. Article 12 states, "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" (United Nations, 2008). Legal capacity is the law's recognition of a person's right to personhood and agency before the law (Arstein-Kerslake, Watson, Browning, Martinis, & Blanck, 2017). The General Comment on Article 12 issued by the Committee on the Rights of Persons with Disabilities emphasizes the need to move away from guardianship to supported decision making (Committee on the Rights of Persons with Disabilities, 2014). It stresses the importance of supported decision making stating that all nations "shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity" (United Nations, 2008). Article 12 has "turned the practice of supported decision making into a human rights imperative" (Arstein-Kerslake et al., 2017, p. 1). In 2014, the Australian Law Reform Commission (ALRC, 2014) strongly supporting supported decision-making practice, articulated that a person's "will, preferences and rights" should be at the heart of laws and legal frameworks, including those regarding supported decision making (p. 11). The ALRC also identified that the "most difficult policy challenges in this area concern those who require the most support," notably where "a person's will and preferences are difficult, or impossible to determine," namely people with PIMD (ALRC, 2014, p. 33).

Realizing Article 12 for People with PIMD

Despite the strength of the paradigm shift brought about by Article 12 of the CRPD, many people with intellectual disability are denied their human right to autonomy. This denial is driven by an assumption that concepts relating to self-determination and autonomy are irrelevant to people with intellectual or cognitive disability, due to perceived limited decision-making capability (Ward & Stewart, 2008; Wehmeyer, 2005). This negative perception of decision-making capability is particularly apparent for people with PIMD.

Although highly heterogeneous, people with PIMD share many life experiences and abilities. They have severe intellectual disability coupled with comorbidities such as motor and sensory impairment making them dependent on others for support in most life areas. People with PIMD generally communicate informally using atypical and idiosyncratic behaviors such as vocalizations, facial expression, gesticulation, shifts in respiration, eye gaze, and touch (Watson, 2016a). Understanding formal communication such as sign, speech, written text, photos, or pictures is challenging for them. Many people with PIMD communicate unintentionally. This means, they appear to communicate without the intention of conveying a message to another person (Bunning, Smith, Kennedy, & Greenham, 2013; Petry & Maes, 2006). Information

transfer occurs when communication partners infer meaning from the person's behaviors. This inference is acknowledged as an ambiguous, subjective, and challenging task (Bradshaw, 2014; Grove, 2007).

These communication challenges have contributed to a historical view that people with PIMD are unable to express their preference in relation to decisions about their lives. Such a view privileges individual cognition, failing to recognize the interdependent nature of the lives of people with PIMD, resulting in the frequent removal of a person's right to autonomy through guardianship. Guardianship (the legal mechanism by which substitute decision making is implemented) involves the appointment of a guardian to make decisions on behalf of a person with disability, removing their human right to legal capacity. In most jurisdictions, decisions to subject a person to guardianship are based on the results of cognitive assessments provided to assist in determination of legal capacity (Darzins, Molloy, & Strang, 2000). Such tools are structured around the traditional premise that decision-making capability is characterized by a set of individual cognitive abilities (problem solving, memory function, rationality, and language) serving as prerequisites for decision-making capability. These skills are often assessed independent of relational factors such as support from family, friends, and support staff. Due to the arguably narrow nature of these assessments, people with PIMD are likely to be assessed as having no or very limited decision-making capability. The legal response to this assessment is to deny legal capacity and permit a third party (legal guardian) to make decisions on behalf of the concerned person; an outcome that has been labeled as a form of "civil death" (Perlin, 2013).

This exclusion from the freedoms set out in Article 12 of the CRPD mirrors past self-determination movements, such as person-centered practice and self-advocacy, dominated by people with mild, as opposed to more severe, intellectual disability (Watson, 2016a). Some commentators equate the cognitive challenges experienced by PIMD, such as difficulties communicating preference intentionally, understanding information, and engaging in rational behavior, with the view that self-determination and autonomy have no relevance to this population (McMahan, 2002; Singer, 1993). These commentators argue that cognitive traits alone are prerequisites to so-called "full personhood." Privileging cognition as central to personhood, they relegate people they view as without these traits to nonperson status, claiming it is reasonable to deny them the moral status and human rights of those with fuller cognitive capacity (McMahan, 2002; Singer, 1993).

The contemporary disability community refutes the idea that personhood, or humanness, should depend on an individual's cognitive ability (Kittay, 2019; Quinn et al., 2018). The emergence of this post-guardianship view is partly due to new insights into how humans actually make decisions. These insights dispute the neoliberal constructions of individualized self-determination, which emphasize individual intellectual "capacity," and explicitly exclude the role which environmental and social factors make to a person's decision making. Human beings do not exercise their self-determination individually, but relationally, interdependently, and intersubjectively with others (Bach & Kerzner, 2010). Furthermore, "When self-determination is interpreted strictly to mean 'doing it yourself,' there is an obvious problem for people with significant disability, many of whom may have limits to the number and types of activities they can perform independently." (Wehmeyer, 1998, p. 10).

Article 12 of the CRPD calls for a universal right to autonomy regardless of intellectual impairment, through supported decision-making mechanisms. Article 12 sets a pathway from guardianship and instead places a presumption of autonomy (with support) at its core. To uphold these obligations, there is a clear need for new tools of discovery to support people with PIMD to form and express their preferences, in relation to all life decisions, including those at the end-of-life. Specifically, there is a need for research that describes the decision-making support for people with PIMD, outlines factors that influence this support, and suggests mechanisms to enhance this support. There is a need for a reframing of the way that decision-making capacity is understood for people with PIMD. This includes a move away from the privileging of individual cognition, instead focusing on the level of supports and adjustments needed in order for people with PIMD to exercise decision-making capacity (Quinn, 2010). So, what should these supports and adjustments look like? One characterization of supported decision making goes some way toward answering this question, suggesting that the process of decision-making support should not be defined in terms of individual capacity but, rather, in terms of the quality of support available:

The starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices. (Beamer & Brookes, 2001, p. 4)

Supported Decision Making: A Mechanism for Realizing Autonomy

Attempts to characterize and develop supported decision-making models and frameworks to guide the practice of supported decision making are emerging (Douglas & Bigby, 2018; Shogren, Wehmeyer, Uyanik, & Heidrich, 2017). However, these models are primarily focused on decision-making support for people with mild, as opposed to more severe, cognitive disability, excluding people with PIMD.

Watson (2016a) implemented a supported decision-making approach (Watson & Joseph, 2015) with a sample of five people with PIMD and their 33 supporters. The participants with PIMD were supported through a collaborative process where their will and preferences were identified, interpreted, explored, and documented by a group of people who knew them well. This information was used ultimately to make a variety of decisions, which ranged from what color to paint a room to whether to have a lifesaving medical treatment. Interview, questionnaire, and observation data were collected and analyzed, resulting in the identification of several themes underlying participation in decision making for people with PIMD. Drawing from this research, decision-making support for people with PIMD can be defined as a process of enhancing the decision-making capacity of a person with PIMD through collaborative support from a group of people in that person's life. A person's circle of support, comprising a group of key people in the person's life, who have a good understanding of the person's life history, preferences, and personal characteristics, is an important ingredient in this process. Within this context, autonomy for a person with PIMD is viewed as a relational construct, best realized in collaboration with those in the person's life who know him or her well (Watson et al., 2017).

Decision-making support for people with PIMD is characterized in terms of the existence of two distinct, but interdependent roles played by (a) the person with a disability (supported) and (b) the circle of support (supporters) in the decision-making process (Watson, 2016a). The role of the person with a disability in this dynamic is his or her expression of preference, and the role of the supporter is to respond to this expression of preference. Within this dynamic, supporter responsiveness is the component that can change, making the enablement of responsiveness a crucial strategy for supporting decision making relating to end-of-life care for people with PIMD.

Responsiveness: A Key Factor in Decision-Making Support for People with PIMD

Researchers have stressed the important and complex role of supporter responsiveness within the process of self-determination and decision making for people with PIMD (Finlay, Antaki, Walton, & Stribling, 2008; Johnson, Watson, Iacono, Bloomberg, & West, 2012; Watson, 2019). Watson's (2016a) qualitative study exploring the implementation of a supported decision-making approach with five people with PIMD provided much needed insights into the complex role of communication partners in the decision-making support process. Watson characterized supporters' role of responsiveness as a multi-faceted activity made up of three tasks. First, supporters acknowledge/notice (as opposed to ignore) expressions of preference of those they support. Second, they interpret these expressions of preference (ideally collaboratively), assigning meaning to them, and finally they assist those they support to act on this meaning. Although each of these tasks is important, none of them characterize responsiveness in isolation. Rather, supporter responsiveness is reliant on the implementation of these tasks collectively (Watson, 2016a).

Acknowledging the importance of responsiveness in the process of decision-making support for people with PIMD, Watson (2016b) identified a range of factors underlying supporter responsiveness that were organized into five overarching themes and 10 subthemes (Watson, 2016b). These overarching factors include (a) the person with PIMD's communication, (b) supporter attitudes and perceptions, (c) relational

closeness between supporter and person with PIMD, (d) functioning and make up of circles of support, and (e) characteristics of the service system. Although each of these themes are important in relation to decision-making support for people with PIMD, the remainder of this article will focus on the role of storytelling (narrative), as a mechanism found to be important in relational closeness and therefore responsiveness within supported decision-making practice for people with PIMD. The authors will explore the application of a narrative approach within the context of decision-making support relating to end-of-life planning and care for people with PIMD.

The Role of Narrative in End-of-Life Decision Making for People with PIMD

Relational closeness is an important factor by which supporters develop a picture of the preferences of those they support (Forster & Iacono, 2008; Watson et al., 2017). A tendency toward greater supporter responsiveness to preference expression has been identified within the context of intimate or very close relationships between supporters and those they are supporting (Watson, 2016a; Watson et al., 2017). Watson et al. (2017) explored the characteristics of relational closeness between a person with PIMD and their communication partners and found that the use of storytelling within interactions between people with PIMD and their supporters was central to relational closeness and therefore supporter responsiveness. The key component of this approach is supporters knowing the history of the person they support, through an exploration of their life story, and through an exploration of their identity beyond the constraints of their disability (Watson, 2016a).

The importance of knowing a person with intellectual disability's history and personal story through narrative approaches, particularly in relation to understanding their preferences, is increasingly being established in the literature (Gjermestad, 2017; Grove, 2007; Koenig, 2012; Schepens, Van Puyenbroeck, & Maes, 2019; ten Brug, van der Putten, Penne, Maes, & Vlaskamp, 2012; Watson et al., 2017). However, for people with PIMD, opportunities for story telling are rare (Grove, 2007; ten Brug et al., 2012). A narrative approach for people with PIMD should recognize the unique nature of their communication (Grove, 2007). This recognition should include the acknowledgment of the nonsymbolic nature of their communication, which is predominantly made up of body language and vocalizations, making them highly dependent on others for the interpretation of their communication signals. A move away from the Anglo-Western approach to narration, emphasizing coherence and resolution, to the storytelling approaches used by non-Western Indigenous people is advocated (Grove, 2007; Sable & Francis, 2012). Within these cultures, where stories are often open-ended, elliptical, and concealed, Grove (2012) makes particular reference to the Mi'kmaw stories of the first peoples of Nova Scotia and the Indigenous peoples of Australia, which do not conform to Western logic for sequencing time. Rather, stories are described as open, filled with possibility, mutability, and ongoing interpretation according to personal and shared experience (Sable & Francis, 2012). Parallels can be drawn between these Indigenous perspectives and the process of interpreting preferences of people with PIMD, whose communication may lack coherence and formality, and yet be highly complex and multilayered (Grove, 2007). This highlights the interdependent nature of Indigenous narrative tradition, a reflection of a collectivist perspective that values relationships, family, and community. "Everything, every person is spoken of in relation with something or someone else . . . everything existed within a network of relationships" (Sable & Francis, 2012, p. 32). This recognition of mutual dependence is of clear relevance to decision-making support for people with PIMD, including as it is applied to the realization of autonomy at the end of life.

The value of using historical narrative within the context of decision-making support has been demonstrated with people with PIMD. Using a decision-making support process, Watson (2016a) guided circles of support to collaboratively develop an understanding of the preferences of those they supported by sharing stories about their past. They shared these stories verbally and, where available, visually, using photos and videos. This collection and sharing of historical narratives were found to facilitate understanding of a person's preferences, a fundamental aspect of a decision-making support for people with PIMD (Watson, 2016b). These collaborative understandings of preference were responded to and built into larger life decisions.

A supporter's willingness to see the person they supported beyond their disability was found to impact their responsiveness to the expressions of preference of those they supported (Watson, 2016a). This notion of seeing a person beyond their disability has been previously described as an important factor in responsiveness to expressions of preference. Lyng (2007) used a strategy whereby he asked supporters questions such as, "If a person you support had complete control over their life, what music might they listen to, what car might they drive or what clothes might they wear?" He found that these questions allowed supporters to view those they supported as having preferences beyond those typically associated with their support needs. Drawing from Lyng's work, Watson (2016a) asked similar questions of circles of support. These questions facilitated the collaborative development of narratives that highlighted perceived preferences of the people with PIMD they were supporting.

A narrative approach as described can be applied to decision-making support at the end-of-life for people with PIMD. Drawing on Watson's (2016a) data, Table 1 demonstrates how a narrative approach can be applied within decision-making support relating to end-of-life decisions.

Implications for Practice

This paper has brought to life several ways practitioners can ensure meaningful end-of-life practices for people with PIMD through sharing of both historical stories as well as narratives about who a person is beyond their disability. Multimedia techniques for gathering, documenting, and sharing historical knowledge have been described and are reflected in the research and practice literature (Bunning, Heath, & Minnion, 2009; ten Brug et al., 2012). The sharing and documentation of historical information were found to be particularly effective for Neil's circle of support (see Table 1) at the end of his life. Neil's circle of support used tools such as a communication diary, verbal narrative, and importantly, video, to explore Neil's previous expressions of preference, particularly in relation to his experiences of a past tracheostomy. Documentation of these historical expressions of preference was used to guide Neil's circle of support in making a collective decision about his end-of-life care.

An additional narrative approach focused on "seeing a person beyond their disability" (Lyng, 2007) has clear application to the process of decision-making support at the end-of-life for people with PIMD. The stories collated about Yuri's life "beyond his disability" (see Table 1) provide a picture of his ideal place of well-being. Those close to him perceive this place as away from the "hustle and bustle" perhaps "in the bush." It is a place familiar to Yuri, where he feels comfortable. Further demonstrating this application, Nathan's perceived music preferences "something with a bit of guts" may assist those supporting him to make decisions about the music he listens to at the end of his life. Narratives describing a person's preferred environments, such as these, may serve as useful mechanisms for supporting people with PIMD to have their environmental preferences reflected in decisions made at the end of life and therefore may form an important part of their advance care plan.

Implications for Research

While there is an increasing focus on understanding and supporting end-of-life preferences for people with milder intellectual disability, the experiences of people with severe intellectual disability continue to be poorly represented in current empirical data (Stancliffe et al., 2017). It is hoped that this article has sparked inspiration for the development of a research agenda focused on maximizing autonomy for people with PIMD at the end of life. The authors suggest five directions for future research: (a) the development of a deeper understanding of the three components of supporter responsiveness, acknowledging, interpreting, and acting on, the expression of will and preference of people with PIMD within a supported decision-making paradigm, both at the end of and throughout a person's life; (b) considering the established importance of relational closeness within decision-making support, further exploration of the factors that underlie the development of close and safe relationships between people with PIMD and their supporters; (c) exploration of health professionals' perspectives, attitudes, and practice concerning people with PIMD in relation to end-of-life decision making and planning; (d) further exploration of the role that historical narrative and

Table 1. Application of a Narrative Approach in Supporting End-of-Life Decision Making for People with PIMD.

Participant	Narrative approach	Details
Kevin	Context	Participants recalling the childhood of a man with PIMD they had known for many years.
	Collective narrative	<p>“Remember. . .he used to sit in the creek. . .loved that water, [he] used to sit there for hours. . .”</p> <p>“Remember that time, Kev, that time in the old place, when you destroyed the bathroom with all that splashing from the bath. It took us hours to mop it up didn’t it, and all you did was laugh, you ratbag!”</p> <p>“We used to take him up to [place name]. He liked to go for a ride in the speedboat. We used to sit him in the speedboat and he used to get excited with the water splashing and that sort of thing.”</p>
	Collaborative interpretation	Kevin enjoys the sounds and texture of water.
	Using a narrative approach in supported decision making relating to end-of-life choices	This information about Kevin’s preferences relating to water may influence the decisions he is supported to make about the environment in which he may die. For example, an advanced care plan for Kevin may detail that Kevin would like to spend his last days near a body of water, where he can be immersed in the sensory experience of water. Kevin’s palliative care may include regular bathing and the playing of the same digital recording (babbling brook) identified by those who know him well as relaxing.
Neil	Context	Because of aspiration pneumonia, Neil and his circle of support were faced with a range of decisions, including whether he should have potentially lifesaving medical treatment (i.e., a permanent tracheostomy) to extend his life. Neil’s circle of support worked collaboratively to consider his options. Those in the circle of support drew upon what they knew about his past experience of a tracheostomy 3 years earlier.
	Collective narrative	<p>“I remember, you do too [looking at Neil’s mother], he hated it. It was horrible. He was so distressed he seemed so scared.”</p> <p>Neil’s past distress was evidenced not only through his supporters’ memories, but also through documentation tools such as a video taken by his mother, and the service provider’s house diary at the time of Neil’s past tracheostomy. Referring to that documentation Neil’s mother said,</p> <p>“Don’t you worry love, I remember. I videoed him on my phone, it was such a Godsend when they got rid of it. If they hadn’t Neil would have pulled it out himself, don’t you worry about that.”</p> <p>Support worker: Have you still got that video? I’d like to see it. I didn’t know Neil back then.”</p> <p>Support worker: “Yes, I’ve seen it—hard to watch. It might be good for us all to see it. Hey, what about the old diary, see what we wrote at that time? I’ll dig it up when I get back to the house.”</p> <p>This evidence was collated and shared with his circle of support who used it to support Neil in his decision making.</p>
	Collaborative interpretation	Neil previously found the tracheotomy as an alternative method of breathing extremely distressing and is likely to find it distressing again.
	Using a narrative approach in supported decision making relating to end-of-life choices	Guided by the preferences Neil had communicated to them through documentation (video and the house diary) of his previous experience, the group collectively made the difficult decision that a tracheostomy would not be carried out. Neil died a number of days later with his mother and father and house supervisor from his residential service by his side.
	Context	Nathan’s circle of support was asked, “If Nathan had control over the stereo in the bus, what would he listen to?”

(continued)

Table 1. (continued)

Participant	Narrative approach	Details
Yuri	Collective narrative	<p>“Oh yeah. . . he likes some like rock type music, like AC/DC. Yeah something with a bit of guts!”</p> <p>“Yeah, you’re right, something with guts, loud, loud, loud! Yeah, louder the better hey Nate! A deep heavy base line don’t ya reckon? Nirvana or may be even Primus.”</p>
	Collaborative interpretation	Nathan likes heavy loud music with a strong baseline.
	Using a narrative approach in supported decision making relating to end-of-life choices	This information about Nathan’s preferences relating to music may influence the decisions he is supported to make about the environment in which he may die. For example, Nathan’s advanced care plan may describe the music that could be played during his palliative care.
	Context	Yuri’s circle of support was asked, “If Yuri could live wherever he wanted, where would he live? What would his home look like? Who would be there?”
	Collective narrative	<p>“That’s so easy. He would be with a small group of people who he really loves. He’s not someone who likes lots of people around. And he really likes his home comforts.”</p> <p>“Doesn’t like being away from home and the people he knows well. He’s a real home body”</p> <p>“I reckon his house would be away from the hustle and bustle of, say, this place. He’d be living in the bush, looking out over a lovely view, and yeah, he’d stay there, he wouldn’t go out much. He really likes being in his familiar environment.”</p>
	Collaborative interpretation	Yuri likes a quiet familiar environment, away from the “hustle and bustle.” This is a place of wellbeing and comfort for him.
	Using a narrative approach in supported decision making relating to end-of-life choices	This information about Yuri’s preferences relating to a quiet environment may influence the decisions he is supported to make about the environment in which he may die. For example, Yuri’s advanced care plan may describe the environment that he would prefer to be at the end of his life. A quiet place <i>perhaps</i> “in the bush” and “away from the hustle and bustle,” surrounded by a small circle of people he is very familiar with.

Note. PIMD = profound intellectual and multiple disabilities.

storytelling can play in understanding will and preference for people with PIMD, particularly in relation to decisions at the end-of-life; and (e) examination of decisions relating to end-of-life care and support (e.g., place of death, resuscitation, medication, funeral plans, assisted dying, people present at the time of death), particularly as they relate to people with PIMD and their circle of support.

Conclusion

Honoring a person’s preferences at the end of life is arguably one of the most profound gifts humans can give to one another. However, little attention has been paid to end-of-life planning for people with intellectual disability, particularly people with PIMD (Tuffrey-Wijne & Davidson, 2018; Voss et al., 2017). This is despite the life expectancy of people with intellectual disability increasing in line with the general population (Coppus, 2013). This lack of attention is arguably driven by an assumption that concepts relating to self-determination and autonomy have no relevance to people with PIMD, due to perceived decision-making incapability. There is little question that those supporting people with PIMD to plan for and make decisions about end-of-life care are faced with a challenge. However, this challenge needs to be undertaken, not only because of the human rights obligations defined in the CRPD but also due to the empirical evidence

demonstrating the importance of autonomy in the creation of a good death (Granda-Cameron & Houldin, 2012). In response to this challenge, this article has drawn on empirical research to promote the value of decision-making support within the context of palliative care and advance care planning for people with PIMD. It promotes the use of storytelling, narrative, and multimedia (photos and video) as an approach to allow people with PIMD to have their expressions of preferences acknowledged and acted upon at the end-of-life. It provides practical examples of how such a narrative approach can be used to support decision making within the context of advance care planning and palliative care for people with PIMD. This article offers guidance for those providing decision making and advance care planning support for people with PIMD who traditionally have not been “heard” in this important stage of life. In addition, conversation as to how nations can live up to their obligations as defined in the CRPD in ensuring the right to autonomy is universal both throughout and at the end-of-life. Finally, the authors hope to have ignited an interest in this under researched area and opened an important conversation aimed at developing a research agenda focused on supporting decision making for people with PIMD in relation to their end-of-life care.


Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Joanne Watson  <https://orcid.org/0000-0001-5015-3492>

References

- Advance Care Planning Australia. (2018). *Advance care planning in victoria*. Retrieved from <https://www.advancecareplanning.org.au/resources/advance-care-planning-for-your-state-territory/vic#fact>
- Anderson, R. J., Bloch, S., Armstrong, M., Stone, P. C., & Low, J. T. S. (2019). Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence. *Palliative Medicine*, 33, 926-941. doi:10.1177/0269216319852007
- Arstein-Kerslake, A., Watson, J., Browning, M., Martinis, J., & Blanck, P. (2017). Future directions in supported decision-making. *Disability Studies Quarterly*, 37(1), 5-5. doi:10.18061/dsq.v37i1.5070
- Australian Commission on Safety and Quality in Health Care. (2015). *National consensus statement: Essential elements for safe and high quality end-of-life care*. Sydney, Australia: Authors. Retrieved from <https://www.safetyandquality.gov.au/sites/default/files/migrated/National-Consensus-Statement-Essential-Elements-for-safe-high-quality-end-of-life-care.pdf>
- Australian Law Reform Commission. (2014). *Equality, Capacity and disability in commonwealth laws* (ALRC Report 234). Canberra: Commonwealth of Australia. Retrieved from <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>
- Bach, M., & Kerzner, L. (2010). *A new paradigm for protecting autonomy and the right to legal capacity*. Ontario, Canada: Law Commission of Ontario. Retrieved from <https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf>
- Beamer, S., & Brookes, M. (2001). *Making decisions. Best practice and new ideas for supporting people with high support needs to make decisions*. London, England: Values into Action.
- Bekkema, N., de Veer, A. J. E., Wagemans, A. M. A., Hertogh, C. M. P. M., & Francke, A. L. (2014). Decision-making about medical interventions in the end-of-life care of people with intellectual disabilities: A national survey of the considerations and beliefs of GPs, ID physicians and care staff. *Patient Education and Counselling*, 96, 204-209. doi:10.1016/j.pec.2014.05.014
- Bloomer, M., Botti, M., Runacres, F., Poon, P., Barnfield, J., & Hutchinson, A. (2018). Communicating end-of-life care goals and decision-making among a multidisciplinary geriatric inpatient rehabilitation team: A qualitative descriptive study. *Palliative Medicine*, 32, 1615-1623. doi:10.1177/0269216318790353
- Bloomer, M., Botti, M., Runacres, F., Poon, P., Barnfield, J., & Hutchinson, A. (2019a). Cultural considerations at end-of-life in a geriatric inpatient rehabilitation setting. *Collegian*, 26, 165-170. doi:10.1016/j.colegn.2018.07.004

- Bloomer, M., Botti, M., Runacres, F., Poon, P., Barnfield, J., & Hutchinson, A. (2019b). End-of-life care for older people in subacute care: A retrospective clinical audit. *Collegian*, 26, 22-27. doi:10.1016/j.collegn.2018.02.005
- Bloomer, M., Digby, R., Tan, H., Crawford, K., & Williams, A. (2016). The experience of family carers of people with dementia who are hospitalised. *Dementia*, 15, 1234-1245. doi:10.1177/1471301214558308
- Bloomer, M., Lee, S., & O'Connor, M. (2011). End-of-life Clinician-family communication in ICU: A retrospective observational study—Implications for nursing. *The Australian Journal of Advanced Nursing*, 28(2), 17-23.
- Bloomer, M. J., & Digby, R. (2012). Caring for patients dying with dementia: Challenges in subacute care in Australia. *Journal of Palliative Care*, 28, 164-168. doi:10.1177/082585971202800306
- Bradshaw, J. (2014). Commentary on "Evaluation of the impact of supervisory support on staff experiences of training." *Tizard Learning Disability Review*, 19, 85-89. doi:10.1108/TLDR-01-2014-0002
- Brazil, K., Carter, G., Cardwell, C., Clarke, M., Hudson, P., Froggatt, K., . . . Kernohan, W. G. (2017). Effectiveness of advance care planning with family carers in dementia nursing homes: A paired cluster randomized controlled trial. *Palliative Medicine*, 32, 603-612. doi:10.1177/0269216317722413
- Bunning, K., Heath, B., & Minnion, A. (2009). Communication and empowerment: A place for rich and multiple media? *Journal of Applied Research in Intellectual Disabilities*, 22, 370-379. doi:10.1111/j.1468-3148.2008.00472.x
- Bunning, K., Smith, C., Kennedy, P., & Greenham, C. (2013). Examination of the communication interface between students with severe to profound and multiple intellectual disability and educational staff during structured teaching sessions. *Journal of Intellectual Disability Research*, 57, 39-52. doi:10.1111/j.1365-2788.2011.01513.x
- Committee on the Rights of Persons with Disabilities. (2014). *General comment no. 1—Article 12: Equal recognition before the law*. CRPD/C/GC/1. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK539188/>
- Coppus, A. M. W. (2013). People with intellectual disability: What do we know about adulthood and life expectancy? *Developmental Disabilities Research Reviews*, 18, 6-16. doi:10.1002/ddrr.1123
- Darzens, P., Molloy, W., & Strang, D. (Eds.). (2000). *Who can decide? The six step capacity assessment process*. Adelaide, South Australia: Memory Australia Press.
- Detering, K. M., Hancock, A. D., Reade, M. C., & Silvester, W. (2010). The impact of advance care planning on end-of-life care in elderly patients: Randomised controlled trial. *British Medical Journal*, 340, c1345. doi:10.1136/bmj.c1345 %J BMJ
- Douglas, J., & Bigby, C. (2018). Development of an evidence-based practice framework to guide decision making support for people with cognitive impairment due to acquired brain injury or intellectual disability. *Disability and Rehabilitation*, 18, 1-8. doi:10.1080/09638288.2018.1498546
- Finlay, W. M. L., Antaki, C., Walton, C., & Stribling, P. (2008). The dilemma for staff in "playing a game" with a person with profound intellectual disabilities: Empowerment, inclusion and competence in interactional practice. *Sociology of Health & Illness*, 30, 531-549. doi:10.1111/j.1467-9566.2007.01080.x
- Forster, S., & Iacono, T. (2008). Disability support workers' experience of interaction with a person with profound intellectual disability. *Journal of Intellectual & Developmental Disability*, 33, 137-147. doi:10.1080/13668250802094216
- George, N. R., Kryworuchko, J., Hunold, K. M., Ouchi, K., Berman, A., Wright, R., . . . Platts-Mills, T. F. (2016). Shared decision-making to support the provision of palliative and end-of-life care in the Emergency Department: A consensus statement and research agenda. *Academic Emergency Medicine*, 23, 1394-1402. doi:10.1111/acem.13083
- Gjermestad, A. (2017). Narrative competence in caring encounters with persons with profound intellectual and multiple disabilities. *International Practice Development Journal*, 7, 1-11. doi:10.19043/ipdj.7SP.007
- Granda-Cameron, C., & Houldin, A. (2012). Concept analysis of good death in terminally ill patients. *American Journal of Hospice and Palliative Care*, 29, 632-639. doi:10.1177/1049909111434976
- Grove, N. (2007). Exploring the absence of high points in story reminiscence with carers of people with profound disabilities. *Journal of Policy & Practice in Intellectual Disabilities*, 4, 252-260. doi:10.1111/j.1741-1130.2006.00088.x
- Grove, N. (2012). Story, agency, and meaning making: Narrative models and the social inclusion of people with severe and profound intellectual disabilities. *Journal of Religion, Disability & Health*, 16, 334-351. doi:10.1080/15228967.2012.731887
- Heslop, P., Blair, P. S., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2014). The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: A population-based study. *The Lancet*, 383, 889-895. doi:10.1016/S0140-6736(13)62026-7
- Johnson, H., Watson, J., Iacono, T., Bloomberg, K., & West, D. (2012). Assessing communication in people with severe-profound disabilities: Co-constructing competence. *Journal of Clinical Practice in Speech-Language Pathology*, 14, 64-68.
- Johnstone, M.-J., Hutchinson, A. M., Redley, B., & Rawson, H. (2015). Nursing roles and strategies in end-of-life decision-making concerning elderly immigrants admitted to acute care hospitals. *Journal of Transcultural Nursing*, 27, 471-479. doi:10.1177/1043659615582088

- Kirkendall, A., Linton, K., & Farris, S. (2017). Intellectual disabilities and decision-making at end-of-life: A literature review. *Journal of Applied Research in Intellectual Disabilities*, 30, 982-994. doi:10.1111/jar.12270
- Kittay, E. F. (2019). *Learning from my daughter: The value and care of disabled minds*. <https://www.oxfordscholarship.com/view/10.1093/oso/9780190844608.001.0001/oso-9780190844608>
- Koenig, O. (2012). Any added value? Co-constructing life stories of and with people with intellectual disabilities. *British Journal of Learning Disabilities*, 40, 213-221. doi:10.1111/j.1468-3156.2011.00695.x
- Lyng, K., (2007, May). *How do you know what I want? Exploring quality of life with people with no functional speech*. Paper presented at the National Disability Services: Aging and Disability Conference, Adelaide, Australia.
- McMahan, J. (2002). *The ethics of killing: Problems at the margins of life*. Oxford, UK: Oxford University Press.
- Perlin, M. (2013). 'Striking for the guardians and protectors of the mind': The convention on the rights of persons with mental disabilities and the future of guardianship law. *Penn State Law Review*, 117, 1159-1190.
- Petry, K., & Maes, B. (2006). Identifying expressions of pleasure and displeasure by persons with profound and multiple disabilities. *Journal of Intellectual & Developmental Disability*, 31, 28-38. doi:10.1080/13668250500488678
- Quinn, G. (2010, February). *Personhood and legal capacity: Perspectives on the paradigm shift of article 12 CRPD*. Paper presented at the Harvard Law School Project on Disability Conference. Cambridge, MA.
- Quinn, G., Gur, A., & Watson, J. (2018). Ageism, moral agency and autonomy: Getting beyond guardianship in the 21st century. In I. Doron & N. Georgantzi (Eds.), *Ageing, ageism & the law: European perspectives on the rights of older persons*. Cheltenham, UK: Edward Elgar.
- Sable, T., & Francis, B. (2012). *The language of this land, Mi'kma'ki*. Sydney, Australia: Cape Breton University Press.
- Schepens, H. R. M. M., Van Puyenbroeck, J., & Maes, B. (2019). How to improve the quality of life of elderly people with intellectual disability: A systematic literature review of support strategies. *Journal of Applied Research in Intellectual Disabilities*, 32, 483-521. doi:10.1111/jar.12559
- Shogren, K. A., Wehmeyer, M. L., Uyanik, H., & Heidrich, M. (2017). Development of the supported decision-making inventory system. *Intellectual and Developmental Disabilities*, 55, 432-439. doi:10.1352/1934-9556-55.6.432
- Singer, P. (1993). *Practical ethics* (2 ed.). Cambridge, UK: Cambridge University Press.
- Stancliffe, R. J., Wiese, M. Y., & Read, S. (2017). End-of-life and people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30, 977-981. doi:10.1111/jar.12383
- Sudore, R. L., Lum, H. D., You, J. J., Hanson, L. C., Meier, D. E., Pantilat, S. Z., . . . Heyland, D. K. (2017). Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. *Journal of Pain and Symptom Management*, 53, 821-832. doi:10.1016/j.jpainsymman.2016.12.331
- ten Brug, A., van der Putten, A., Penne, A., Maes, B., & Vlaskamp, C. (2012). Multi-sensory storytelling for persons with profound intellectual and multiple disabilities: An analysis of the development, content and application in Practice. *Journal of Applied Research in Intellectual Disabilities*, 25, 350-359. doi:10.1111/j.1468-3148.2011.00671.x
- Tuffrey-Wijne, I., & Davidson, J. (2018). Excellence in palliative and end-of-life care provision for people with intellectual disability. *International Journal of Palliative Nursing*, 24, 598-610. doi:10.12968/ijpn.2018.24.12.598
- Turner, V., & Flemming, K. (2019). Socioeconomic factors affecting access to preferred place of death: A qualitative evidence synthesis. *Palliative Medicine*, 33, 607-617. doi:10.1177/0269216319835146
- United Nations. (2008). *Convention on the rights of persons with disabilities* (United Nations Treaty Series, vol. 2515, No. 44910). Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- Visser, P., Dwyer, A., Moran, J., Brittin, M., Heland, M., Ciavarella, F., & Jones, D. (2014). Medical emergency response in a sub-acute hospital: Improving the model of care for deteriorating patients. *Australian Health Review*, 38, 169-176. doi:10.1071/AH13245
- Voss, H., Francke, A. L., de Veer, A. J. E., Vogel, A., Wagemans, A. M. A., Courtens, A. M., & Metsemakers, J. F. M. (2017). Advance care planning in palliative care for people with intellectual disabilities: A Systematic Review. *Journal of Pain and Symptom Management*, 54, 938-960. doi:10.1016/j.jpainsymman.2017.04.016
- Voss, H., Vogel, A., Wagemans, A. M. A., Francke, A. L., Metsemakers, J. F. M., Courtens, A. M., & Veer, A. J. E. (2019). Advance care planning in the palliative phase of people with intellectual disabilities: Analysis of medical files and interviews. *Journal of Intellectual Disability Research*, 63, 1262-1272. doi:10.1111/jir.12664
- Ward, T., & Stewart, C. (2008). Putting Human Rights into Practice with People with an Intellectual Disability. *Journal of Developmental & Physical Disabilities*, 20, 297-311. doi:10.1007/s10882-008-9098-4
- Watson, J. (2016a). Assumptions of decision-making capacity: The role supporter attitudes play in the realisation of Article 12 for people with severe or profound intellectual disability. *Laws*, 5(1), 1-9. doi:10.3390/laws5010006
- Watson, J. (2016b). *The right to supported decision-making for people rarely heard* (Doctoral dissertation). Retrieved from <http://dro.deakin.edu.au/view/DU:30083812>

- Watson, J. (2019). The role of speech-language pathology in supporting legal capacity. *Journal of Clinical Practice in Speech-language Pathology*, 21(1), 25-28.
- Watson, J., & Joseph, R. (2015). *People with severe to profound intellectual disabilities leading lives they prefer through supported decision-making: Listening to those rarely heard. A guide for supporters: A training package* (2nd ed.). Melbourne, Australia: Scope.
- Watson, J., Wilson, E., & Hagiliassis, N. (2017). Supporting end-of-life decision-making: Case studies of relational closeness in supported decision-making for people with severe or profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30, 1022-1034. doi:10.1111/jar.12393
- Wehmeyer, M. (1998). Self-determination and individuals with significant disabilities: Examining meanings and misinterpretations. *Journal of the Association for Persons with Severe Handicaps*, 23, 5-16. doi:10.2511/rpsd.23.1.5
- Wehmeyer, M. (2005). Self-determination and individuals with severe disabilities: Re-examining meanings and misinterpretations. *Research and Practice for Persons with Severe Disabilities*, 30, 113-120. doi:10.2511/rpsd.30.3.113
- Witham, M. D., & Hockley, J. (2016). A good death for the oldest old. *Age and Ageing*, 45, 329-331. doi:10.1093/ageing/afw056
- Young, H., Hogg, J., & Garrard, B. (2017). Making sense of bereavement in people with profound intellectual and multiple disabilities: Carer perspectives. *Journal of Applied Research in Intellectual Disabilities*, 30, 1035-1044. doi:10.1111/jar.12285
- Zaal-Schuller, I. H., Willems, D. L., Ewals, F. V. P. M., van Goudoever, J. B., & de Vos, M. A. (2016). How parents and physicians experience end-of-life decision-making for children with profound intellectual and multiple disabilities. *Research in Developmental Disabilities*, 59, 283-292. doi:10.1016/j.ridd.2016.09.012

Author Biographies

Joanne Watson is a lecturer in the School of Health and Social Development and co-director of the postgraduate disability and inclusion program at Deakin University in Victoria, Australia. Her research focuses on protecting the human rights of people with complex communication and support needs.

Hille Voss is a doctoral student at the Netherlands Institute of Health Services Research (Nivel) in Utrecht, the Netherlands. Her research focusses on advance care planning in end of life care for people with intellectual disability.

Melissa J. Bloomer is a senior lecturer in the School of Nursing and Midwifery at Deakin University in Victoria, Australia. Her research interests focus on end-of-life and palliative care, dementia, communication, and decision-making.

Received: August 27, 2019

Final Acceptance: September 11, 2019

Editors-in-Charge: Meghan M. Burke and K. Charlie Lakin