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Decision making by people with intellectual disabilities
A review of the literature

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Abstract

The right of people with intellectual disabilities to make decisions remains controversial despite the policy turn towards support promoted by the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). Supported decision making is an alternative model to substitute decision making, shifting the focus from the assumption of incapacity to the provision of individualised support to exercise this right. Despite the centrality of decision making for the development and implementation of policy and legislation, there is limited understanding of the experiences of people with intellectual disabilities and of persons supporting them. A literature review was conducted to understand these experiences and perspectives. A systematic search from 2000 to 2023 identified a total of 33 articles that were examined through reflexive thematic analysis and adopting an inclusive research approach. The review reveals the experiences of people with intellectual disabilities making day-to-day decisions and more long-term decisions. Trusted relationships with family and staff who provide support are critical to enable decision making, however, numerous restrictions to decision making have been reported. Open dialogue, accessible information, knowing the person with disability well, responsiveness to their wills and preferences, advocating for their rights, providing learning experiences, using planning tools, and having a shared vision for the person as capable of making their own decisions are presented as enablers of decision making. Support can be adapted to enable people with intellectual disabilities to have control over their decisions. Careful examination of the more systemic restrictions imposed on and internalised by people with disabilities—a form of substituted decision-making—resulting from a still prevalent protection and «best interest» approach is required to protect people's rights to make decisions.

Plain English abstract

- People with intellectual disabilities have the right to make decisions.
- The Convention on the Rights of Persons with Disabilities promotes support to make decisions.
- Before the Convention and still nowadays, other people have made decisions for people with intellectual disabilities.
- However, we don't know much about what is like for people with intellectual disabilities to make decisions and for supporters to help them.
- We looked at 33 studies on this topic.
- Studies were written between 2000 and 2023.
- We came up with key themes:
  1. People with intellectual disabilities make decisions about different things in their lives, from day to day decisions such as what to eat to big decisions such as where they live or work.
  2. Trusting relationships with family and staff who provide support is very important to enable decision making.
  3. Staff and families have control over many decisions people with intellectual disabilities make.
  4. Talking openly, knowing the person they are supporting well, responding to their wills and preferences, advocating for their right to make decisions, having a vision for the person as capable of making decisions, accessible information, the use of planning tools and learning opportunities help people with intellectual disabilities make decisions.
- It is important to carefully look at decisions that staff and family make on behalf of persons with disabilities in «their best interests» and to protect them.

1. Introduction

The Convention on the Rights of Persons with Disabilities (CRPD) has marked a paradigm shift in thinking about persons with disabilities, from objects of charity to subjects with rights (United Nations, 2006). At the core of the CRPD is article 12, *Equal recognition before the law*, which makes two fundamental conceptual leaps in the recognition of persons with disabilities' right to make decisions. First, regardless of mental capacity, the CRPD reaffirms everyone's right to legal capacity. Mental capacity has been traditionally used as a requirement for people to exercise their legal capacity and it has been discriminatorily used against those with intellectual disabilities and those with mental health problems (Flynn, 2018). Second, State parties' responsibility is to provide the necessary support to people with disabilities to exercise their legal capacity, rather than to deprive them from it (Flynn & Arstein-Kerslake, 2014). A model of supported decision making underpins the CRPD and replaces the long-standing substituted decision making model, where persons with disabilities' decisions are made by someone else on their behalf. Legislation has been developed internationally to align with article 12 of the CRPD, although provisions for substituted decision making are often allowed in the legislation (e.g., «Assisted Decision Making (Capacity) Act» (Government of Ireland, 2015, 2023) (Flynn, 2018).

Brown and Brown (2009) define decision making as thinking about the options, making your mind about it and saying it to others. Decision-making and causal agency are key components of self-determination (Wehmeyer, 2005). Higher levels of self-determination have been linked to positive outcomes in the community and to overall better quality of life (Agran et al., 2010). People with intellectual disabilities are often dependent on family and support staff to make decisions (van der Meulen et al., 2018). Support is even more relevant in relation to persons identified as having severe or profound intellectual disability. Watson et al. (2017) have described supported decision making as a «process of enhancing the decision making capability of people with severe or profound intellectual disability through collaborative support from a group of people in the relevant person's life who know them». However, several problems have been identified in the literature to support persons with intellectual disabilities making decisions and for them to be acted upon (Agran et al., 2010; Bigby et al., 2019; Carey, 2021; Nicholson et al., 2021; Timmons et al., 2011; van der Meulen et al., 2018; Watson et al., 2017; Webb et al., 2020). The goal of self-determination is for people to make things happen, to make decisions and become causal agents in their lives (Wehmeyer, 2005). As Agran et al. (2010) argue, it is «both self-defeating and meaningless to allow consumers to make choices that cannot be realised» (p. 86).

Research on the experiences of people with intellectual disabilities making decisions and being supported to do so is nevertheless in «its infancy» (Carey, 2021, p. 3). Internationally, Carey et al. (2023) found a lack of interventions supporting adults with intellectual disabilities in autonomy and self-determination. Interventions were mostly targeted at those with moderate to mild intellectual disabilities, short term, delivered along other day activities and although developing participants' autonomy did not guarantee that autonomy was sustained over time, participants with intellectual disabilities valued that the interventions had helped staff to know them better (Carey et al., 2023). Training on decision making support can have positive impact on supporters' confidence and strategies (Then et al., 2023) although in two consecutive reviews of international programmes of supported decision making, difficulties were found to recruit supporters (Bigby et al., 2017; Then et al., 2023). Enablers of self-determination in autonomy support interventions are skills development (e.g., decision-making, self-awareness, self-expression, problem solving), use of technology, increased opportunities for functioning independently, working on self-determined plans (Bigby et al., 2017; Carey et al., 2023; Then et al., 2023) and mentorship for supporters (Bigby et al., 2017; Then et al., 2023). Previous research has reported overall positive outcomes for decision makers (Bigby et al., 2017; Then et al., 2023). Carey et al. (2023) notice the lack of research on participants'

experiences and the need to gather their perspectives to improve the interventions. In a literature review on decision making and end of life, Kirkendall et al. (2017) found that others' assumptions about lack of capacity and the need to be protected prevented people with intellectual disabilities from making decisions about the end of life. Issues with the assessment of capacity such as the lack of a standard process and communication difficulties were recurrently mentioned (Kirkendall et al., 2017). When people were deemed not capable, third parties made decisions for them, based on their values and their own perceptions of quality of life, which may be different to those of the individual with intellectual disability (Kirkendall et al., 2017). Decisions about the end of life are further complicated by families' emotional involvement and lack of experience, which have been also found in Bigby et al. (2017), and talking about death being taboo (Kirkendall et al., 2017).

Given the limited exploration of participants' perspectives on decision making, a literature review was conducted to explore the extant research with a focus on the experiences of people with intellectual disabilities making decisions and of those providing support. The literature review reported in this article was part of a larger research project on decision making support conducted by the Inclusive Research Network, a group of researchers with intellectual disabilities and supporters who conduct research about intellectual disability in Ireland (García Iriarte et al., 2021).

2. **Methodology**

The authors followed the five phases proposed by Petticrew and Roberts (2006) to conduct literature reviews: 1) search for potentially relevant articles in databases (i.e., ERIC, PsycINFO, Scopus, and Web of Science) using bolean combinations and relevant variations of key terms (i.e., decision making, experiences, intellectual disability, choice, support);

2) read the titles and abstracts of the retrieved articles; 3) evaluate the articles identified in the previous phase by reading them in full; 4) select the articles of relevance for the present research; and 5) extract and analyse the findings of selected articles. This procedure is represented following the Preferred Reporting Items for Systematic Reviews (PRISMA; Rethlefsen et al., 2021) in Figure 1.

Articles had to meet the following inclusion criteria: 1) focus on decision making by adults with intellectual disabilities; 2) include the perspective of people with intellectual disabilities and/or people supporting them; 3) be peer-reviewed; 4) describe the methodology used; 5) be published in English after the year 2000. A first screening of titles and abstracts by the second author identified 211 potentially relevant articles. Following manual searches of the articles bibliographies, 126 further articles were identified resulting in a total of 337. Upon review of the methodology and aims, 116 articles were selected and read in full. Only 33 of these were deemed to meet the inclusion criteria, exported to Endnote online and shared with the first author for full review. Table 1 outlines the reasons for exclusion. The selected articles and their characteristics are described in Table 2.

We followed the steps for reflexive thematic analysis by Braun and Clarke (2021): 1) familiarisation with the data; 2) generation of initial codes; 3) search for themes; 4) review the themes; 5) define and name these themes; and 6) write the report.

The following approach was adopted to conduct the literature review and to write this article. The first author, a supporter of the Inclusive Research Network proposed to members of the group, who were involved in a larger project on decision making support, and to the second author, a visiting researcher at the first author's institution, who had conducted a preliminary search of the literature, to carry out a literature review for publication in a journal article, which would be later disseminated in plain English with pictures (García Iriarte et al., 2024). The second author and eight members of the Inclusive Research Network agreed to take part. The first two authors read the 33 articles, conducted preliminary thematic analyses, and wrote up a draft of the article. The authors who were members of the

Inclusive Research Network and three supporters gave feedback on the preliminary themes (based on the review of 10 articles), on the final themes after all the articles had been read, reviewed the plain English summary, provided quotes for the discussion section (in quotation marks) to differentiate their voices from the academic authors (Strnadova & Walmsley, 2018) and reviewed a version of the article with their comments identified to confirm agreement for publication.

Figure 1: PRISMA diagram of the process

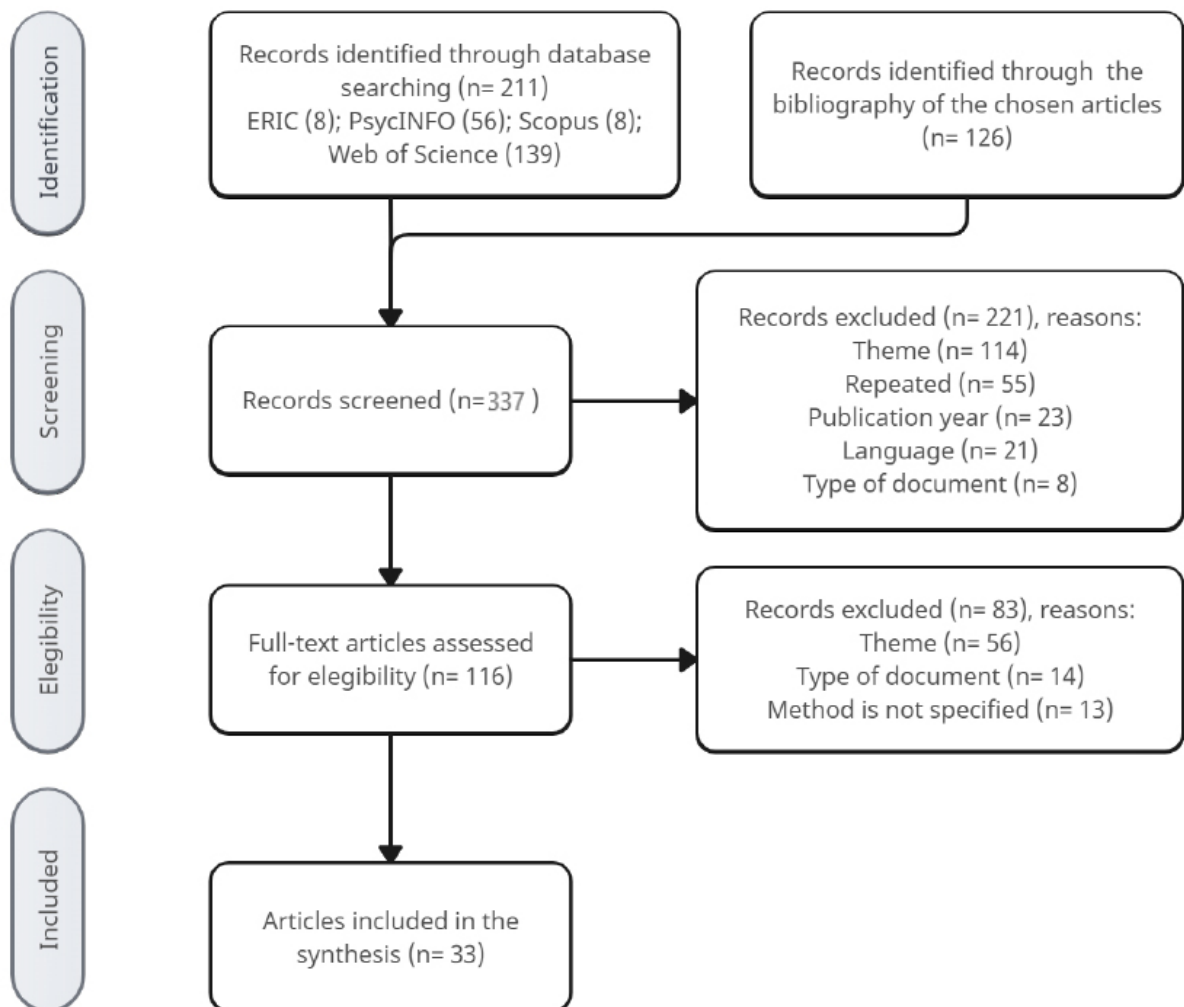**Table 1: Reasons of exclusion after full-text assessment**

	Reason for exclusion after full-text assessment	Excluded articles (n =83)
1	The research is not focused on the topic of decision-making	56
2	The document is not a peer-reviewed article	14
3	The article does not specify the objectives and/or the methodology	13

3. Findings

3.1. Theme 1. Power and control

The literature reviewed indicates that people with intellectual disabilities have experiences of making decisions in several areas such as living in the community (Pallisera et al., 2021; Rubio-Jimenez & Kershner, 2021; Webb et al., 2020), employment (Agran et al., 2010; Timmons et al., 2011; Wass et al., 2021), leisure and activities (Harding & Taşcıoğlu, 2018), everyday routine tasks or healthcare, education and purchases (Webb et al., 2020), pregnancy (Conder et al., 2011), and end of life (Watson et al., 2017). While examples were found of people with intellectual disabilities stating that staff took their choices seriously (Agran et al., 2010) and of being adamant about their right to make decisions, as stated by one participant «to move or not to move flat is my decision» (Rubio-Jimenez & Kershner, 2021, p. 6), options for decision making were often limited.

Several articles have reported an abundance of situations where choices for people with intellectual disabilities are limited by the context, such as in rural areas where the availability of services is scarce (Wark et al., 2015), and more generally, options are restricted by staff and family members to protect persons with intellectual disabilities from risks to their health and overall well-being (Bigby et al., 2019; Bowey, 2005; Cithambaram et al., 2020; Collings et al., 2019; Ferguson et al., 2011; McGlaughlin et al., 2004; van der Meulen et al., 2018; Wass et al., 2021). Restricted options have been often justified by family members acting «realistically» to shape the decision making agenda (Bigby et al., 2019). Decisions about contraception have been reported to be mostly made by others such as family (Chou & Lu, 2011; Horner-Johnson et al., 2022; McCarthy, 2009), and similarly, employment decisions have been made by staff (Agran et al., 2010), or delegated to job developers, given the job developer's expertise in employment (Timmons et al., 2011). Additional areas with little participation by people with intellectual disabilities in decision making include end of life (Watson et al., 2017),

organisational processes, systems, and respite services (Gadd, 2020). Limited options and lack of experience making decisions (McDermott & Edwards, 2012) have resulted in people with intellectual disabilities being deprived from the power and control over decision making, which has led, in turn, to their dissatisfaction (McGlaughlin et al., 2004; Webb et al., 2020), as one participant put it «I should have been asked» (Webb et al., 2020, p. 5).

A particular tension noted in the literature relates to the influence that staff and family members have about choices that are in people with intellectual disabilities' «best interests». For example, Ferguson et al. (2011) noted this tension between people making their own choices and staff educating them to make the «right choice» (according to staff) about their health. Carey (2021) discusses this tension in relation to the flow of control, where adults with intellectual disabilities assimilate what they are told to do and are then self-directed in decision-making (i.e., making decisions in line with what they have been told), and similarly, van der Meulen et al. (2018) note agreement between carers and persons with intellectual disabilities in relation to the personal benefits of diet and bedtime restrictions, where persons with intellectual disabilities internalise that the reasons for their restrictions are in their benefit. Families' involvement in day-to-day activities was seen as an influential factor in choice and decision making by persons with intellectual disabilities (Curryer et al., 2018). The more involved families were in day-to-day activities, the lower the control by the person in decision making. This tendency to internalise significant others' opinions and choices as people with intellectual disabilities' own wishes is closely related to their dependence on them (McCarthy, 2010; Neuman, 2020), resulting in an influence that workers admitted was easy to have, according to Bigby et al. (2019). Carey (2021) argues that adults with intellectual disabilities are neither totally controlled nor totally in control of their decisions but move between this continuum of control. Bigby et al. (2019) found that the support alternates between neutral —respecting decisions even if they are not the preferred options of supporters— and realistic, that is, shaping the decision-making agenda

of the person and restricting their options to what is considered «realistic» by the supporters.

Overriding people with intellectual disabilities' preferences was, regrettably, a common phenomenon in the articles reviewed, which exposes the assumptions by staff and family members about people with intellectual disabilities' limited capacity to understand the decisions they are making and/or the consequences of these decisions (Bowey, 2005; Collings et al., 2019; Curryer et al., 2018; Ferguson et al., 2011; Neuman, 2020; Pilnick et al., 2010) and the long-standing debate about ensuring safety, supporting dignity of risk, and enabling autonomous decision-making (Bigby et al., 2019; Bowey, 2005; Ferguson et al., 2011).

3.2. Theme 2. Decision making support by families, professionals and others

Support is critical for some people with intellectual disabilities to express their views and does not take away from people's self-determination (Bowey, 2005; Martin et al., 2021). Persons with intellectual disabilities have also reported having support to make decisions by their families, professionals and other sources of social support (Conder et al., 2011; Curryer et al., 2018; Webb et al., 2020). In Webb et al. (2020) study, three different types of support were identified: practical (e.g., medication management, appointments), informational (e.g., reading and explaining), and emotional, which could be also provided by peers (e.g., encouragement to be independent, reassurance on decisions, having a wide support network).

Providing decision making support is an integral aspect of the relationships between persons with intellectual disabilities and their supporters according to Bigby et al. (2019). Further, trust in the relationships is essential to share their goals with supporters and for the latter to understand who the person with disability is and what is important to them (Collings et al., 2019; Harding & Taşcıoğlu, 2018; Webb et al., 2020; Williams & Porter, 2017). Knowing the person well has been reported in several

articles as a key factor to facilitate decision making, which involves an overall knowledge of the person, their history, and communication style (Bigby et al., 2019; Ferguson et al., 2011; Harding & Taşcıoğlu, 2018; Watson et al., 2017; Webb et al., 2020). For people with communication difficulties, relational closeness facilitated responsiveness of supporters to the wills and preferences of the person and, further to the above, involved enjoyment of their company and willingness to see the whole person and not only their disability (Watson et al., 2017). While family members took their knowledge of an individual for granted and advised support staff to invest themselves in knowing the person (Bigby et al., 2019), this does not necessarily involve knowing the person for a long time but having access to information from those who have it (Watson et al., 2017) and providing consistent support over time (Collings et al., 2019; Harding & Taşcıoğlu, 2018; Webb et al., 2020).

Having a shared vision for the person (Bigby et al., 2019; Timmons et al., 2011) and advocating for people's rights to make decisions (Bowey, 2005; Collings et al., 2019) are important elements to support decision making. As illustrated by Timmons et al. (2011), families' expectations of the person and role-modelling influenced people's decisions to pursue employment, as work was seen as a desirable life outcome for all members of the family. The overall aim of support is to be guided by the wishes and preferences of the person (Collings et al., 2019). Therefore, advocacy for the person's rights and having deep awareness of the disability experience have been identified as enablers of decision making (Collings et al., 2019). However, tensions can arise also when advocating for the rights of persons with intellectual disabilities, as reported by Bollig et al. (2016), where residents trusted their relatives when coming to a decision about treatment, but relatives felt insecure about the residents' wishes.

Decision making support is seen as a process shared with other people (Bigby et al., 2019; Bollig et al., 2016; Bowey, 2005; Ferguson et al., 2011). Cooperation, however, has not been identified as a feature between professional groups (e.g., regarding referrals) (Bowey, 2005), and conflict has been documented between families and professionals

(Bowey, 2005), who may share different values and approaches (Bigby et al., 2019) as well as between the decision supporter and others involved in the decision maker's life (Bigby et al., 2019). Staff turnover has been seen as a difficulty to support decision making (Ferguson et al., 2011).

There was overall consensus in the literature that communication is a very important factor enabling decision making, between the person with intellectual disability and their supporters, and between the supporters themselves (Cithambaram et al., 2020; Ferguson et al., 2011). On the contrary, failing to communicate information about health issues left people with intellectual disabilities without a voice to make decisions about them (Cithambaram et al., 2020). Dialogue lies at the core of supporting decision making, allowing persons with intellectual disabilities to express their ideas and intentions, enabling genuine negotiations and agreements when it does not seek pre-defined answers (Rubio-Jimenez & Kershner, 2021). Importantly, the role of persons with communication difficulties is to state their wills and preferences while the role of supporters is to respond to the person by combining the following tasks: acknowledging instead of ignoring, interpreting by assigning meaning to them, and acting on the expressed wills and preferences (Watson et al., 2017). Expression of wills and preferences by persons who do not use speech, sign language or other alternative means of communication can be enacted through the lack of engagement in an activity (for example, pretending to be asleep), and active resistance to engage before or during the activity (e.g., walking away) (Nicholson et al., 2021). Understanding of communication cues is enhanced by relational closeness (Watson et al., 2017) and time to communicate is an important enabler of decision making support (Sykes et al., 2022), which are critical for people with intellectual disability who might not feel assertive enough to ask for help (Webb et al., 2020). Insightfully, supporters' role communicating with persons with disabilities has been identified as the target to be changed, instead of the person's communication style, in line with a social model of disability (Cithambaram et al., 2020; Watson et al., 2017).

Supporters also noted a need to be informed about the decisions they were supporting, for example, housing options (Bowey, 2005). Information to facilitate decision making had to be also in accessible formats posing, otherwise, an additional challenge to supporters who were left without resources, as reported in Sykes et al. (2022) study, «once the letter for screening comes in, it's down to the family to explain to them» (p. 5).

The following professional skills have been identified in the literature to facilitate decision making: attention to communication, education about practicalities and consequences, listening and engaging, creating opportunities (Bigby et al., 2019), and understanding emotional responses to control beliefs (Carey, 2021). Personal development of people with intellectual disabilities including self-awareness, confidence and self-advocacy have been also identified to facilitate this process (Bigby et al., 2019; Martin et al., 2021; McCarthy, 2010; Neuman, 2020).

3.3. Theme 3. Other supports and barriers to make decisions

A third theme identified in the literature related to the additional support and barriers that could facilitate or inhibit decision making by persons with intellectual disabilities: understanding information, learning opportunities, and planning.

Understanding the information on which decisions were being made, the available options, and the consequences of the decision was highlighted in Conder et al. (2011) study about pregnancy. Participants' lack of knowledge about the assessment process acted as a barrier to informed decision making, resulting in their surprise when their child was removed from their care (Conder et al., 2011). Information and understanding were also identified in Sykes et al. (2022) study in which participants were aware of the importance of cancer screening but unaware of the specific symptoms of cervical cancer. Accessible information was identified by persons with intellectual disabilities as a key resource to make decisions (McGlaughlin et al., 2004),

however, accessible information was not necessarily available in relation to respite (Gadd, 2020) or contraception (McCarthy, 2009), resulting in women not understanding how contraception works or why particular methods had been suggested for them (McCarthy, 2010). The provision of accessible information, instead of telling people how to follow a healthy lifestyle, would enable them to be more self-determined (Martin et al., 2021). The use of open questions to facilitate choice making between multiple options also seems useful to support decision making (Antaki et al., 2008).

Learning opportunities and learning from mistakes were reported as positive experiences to develop decision making capacity (Collings et al., 2019). For example, in Timmons et al. (2011) study, teachers first provided work experiences as learning opportunities, which helped participants determine the type of job interests, preferences, and careers they wanted to pursue. Curryer et al. (2018) study findings resonate with the above as participants experienced self-determination through learning experiences. Generally, it was identified that the opportunity to learn how to make decisions was beneficial (Agran et al., 2010).

Planning was identified as a helpful tool to think about decisions in relation to everyday activities and more significant life events (Collings et al., 2019). The use of planning tools such as Planning Alternative Tomorrows with Hope (PATH) and support from people who had been through the planning process were reported as helpful to making decisions (Collings et al., 2019). Peer support for decision making was also identified by Webb et al. (2020), who reported participants' accounts of supporting others through planning and decision making (Webb et al., 2020).

4. Discussion and conclusions

The findings of this review contribute to a more comprehensive understanding of decision making through its focus on the experiences of people with intellectual disabilities (Carey et al., 2023) and supporters. This literature review also takes a novel inclusive approach to reviewing the literature. The themes presented in the previous section were discussed by all the authors and a summary of the key points is presented next. Comments by members of the Inclusive Research Network are in quotation marks to differentiate them from the academic authors. Comments identified with names follow the respective author's decision to have their own opinions recognised.

«It's excellent people with intellectual disabilities are making these decisions» (Gavin Morris). Finding out that people with intellectual disabilities were able to make decisions in several areas is in line with the Convention on the Rights of Persons with Disabilities (UN, 2006) and there was a strong sense that «people have their own right to make decisions» (Pauline Skeehan). However, we noted the difficulty when we discussed the tensions around control and best interests between persons with intellectual disabilities, family members and staff, «it's hard to say what you want» (James Delaney) and «it is hard to think about this» (Christina Burke). Kirkendall et al. (2017) found that others' assumptions of lack of capacity and the need for protection prevented people with intellectual disabilities from making decisions. Authors who supported members of the Inclusive Research Network noted how supporters are biased, they have their own opinions and people they support are used to follow their advice, in order to feel socially accepted. As one of the supporters put it, sometimes it is hard to find the confidence for people with intellectual disabilities «to speak out your mind». This review found that developing self-awareness, self-expression and self-advocacy skills of people with intellectual disabilities was an enabler of decision making, which resonates with previous research (Bigby et al., 2017; Carey et al., 2023; Then et al., 2023).

The need for support was recognised by authors «I think you need help and support to make your decisions» (James Delaney) and «I need support because I have a bit of memory loss» (Christina Burke). Good support was also acknowledged «I have great support from family and supporters» (Gavin Morris). We agreed that «people with intellectual disabilities might be or can be more dependent» (Orla McMahon) but are not always dependent and «families might intervene too much» (Christina Burke). Kirkendall et al. (2017) noted the risk when a third person makes decisions on behalf of the person with disability, as their values and their perception of the quality of life of the person may be different to that of the person. Christina Burke stated that «sometimes is hard to explain what you want». Information has to be accessible for both persons making decisions and their supporters and «having enough time for planning is very important to enable decision making» (Christina Burke, Helen O'Reagan). Providing support to supporters can enable decision making, which resonates with the findings by Bigby et al. (2017) and Then et al. (2023). We noted that «even when the decision is made, there is no support to follow it through» (Christina Burke), and «often the supports are not there when you need them» (Helen O'Reagan, Elaine Leonard), which is critical to achieve self-determination and be causal agents in our lives (Wehmeyer, 2005).

In conclusion, while advances have been made, several challenges remain to enable supported decision making respecting the wills and preferences of the person. Rights training for supporters, skills to respond to persons' wills and preferences and sustaining the support to follow through their decisions, self-expression and advocacy skills for persons with intellectual disabilities, availability of accessible information, enabling time for planning and using planning tools are key enablers of decision making. A systems approach that enables equal opportunities, rather than piecemeal fixes, needs to be adopted for persons with disabilities to exercise their right to make decisions and avail, if needed, of support.

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Table 2. Selected articles

	Author(s) and year	Country	Area of Decision-Making	People involved		Method of data collection and analysis
				With intellectual disabilities	Others	
1	Agran et al., 2010	USA	Employment	114 adults	None	Survey; Interviews; Descriptive analysis
2	Antaki et al., 2008	UK	Housing	5 men	Staff members	Ethnography; Conversation analysis
3	Bigby et al., 2019	Australia	Daily Life	None	11 family members; 12 workers in disability support	Focus groups; Interviews; Inductive thematic analysis
4	Bollig et al., 2016	Germany; Norway	End of Life	25 adults	18 relatives	Interviews; Focus groups; Interpretative description
5	Bowey et al., 2005	UK	Housing	None	Family carers; Professionals	Focus groups; Interviews; Inductive thematic analysis
6	Carey, 2021	Ireland	Choice and autonomy	12 adults	None	Interviews; Informal discussions
7	Chou & Lu, 2011	Taiwan	Sterilization	11 women	11 primary carers	Semi-structured interviews; Thematic analysis
8	Cithambaran et al., 2020	Ireland; UK	End of Life	11 adults	8 family members	Interviews; Constant comparative method
9	Collings et al., 2019	Australia	National Disability Insurance	9 adults	None	Focus groups; thematic analysis
10	Conder et al., 2011	UK	Pregnancy and parenting	19 people, 4 stories analysed	None	Interviews; inductive approach
11	Curryer et al., 2018	Australia	Family relationships	8 adults	None	Interviews; Interpretative Phenomenological analysis
12	Ferguson et al., 2011	UK	Healthcare	4 adults	13 primary carers; 4 physiotherapy staff	Interviews; focus group; thematic analysis
13	Gadd, 2020	Ireland	Respite centres	28 adults	None	Interviews; Focus Groups; Thematic analysis
14	Harding & Taşcıoğlu, 2018	UK	Supports to decision-making	15 adults	6 supporters; 25 social care professionals	Interviews; Thematic analysis
15	Horner-Johnson et al., 2022	USA	Contraceptive methods	4 women	14 women with other types of disabilities	Focus groups; Conventional content analysis
16	Martin et al., 2021	Ireland	Diet	8 adult students	5 ID nurses	Collaborative patient and public involvement approach
17	McCarthy, 2009	UK	Contraceptive methods	23 women	None	Interviews; Multistage narrative analysis

	Author(s) and year	Country	Area of Decision-Making	People involved		Method of data collection and analysis
				With intellectual disabilities	Others	
18	McCarthy, 2010	UK	Contraceptive methods	23 women	162 doctors	Interviews; Survey; Multistage narrative analysis
19	McDermott & Edwards, 2012	Australia	Retirement	43 older adults	30 service providers	Interviews; Thematic analysis
20	McGlaughlin et al., 2004	UK	Housing	72 adults	None	Questionnaires administered as interviews; descriptive statistics; thematic analysis
21	Neuman, 2020	Israel	Life journeys	6 adults	None	Interviews; Mapping
22	Nicholson et al., 2021	UK	Social Services	5 adults	12 staff members	Ethnography; Conversation analysis
23	Pallisera et al., 2021	Spain	Supported living	13 adults	6 support professionals	Interviews; Directed content analysis
24	Pilnick et al., 2010	UK	Daily life	28 young adults	Carers and professionals	Interviews; Discussion groups; Conversation analysis
25	Rubio-Jimenez & Kershner, 2021	Mexico	Independent Living	6 adults	None	Discussion sessions, participant observation; Thematic analysis
26	Sykes et al., 2022	UK	Cervical and Breast cancer screening	12 women	3 family carers and 5 paid care workers	Q methodology, Q sort statements and Q sort interview; Factor analysis using PQ method and framework analysis
27	Timmons et al., 2011	USA	Employment	16 adults	13 family members and 15 employment support	Interviews; Thematic analysis
28	van der Meulen et al., 2018	Netherlands	Evaluation of restrictions	8 adults	8 key staff persons	Interviews; Review of clinical files; Thematic analysis
29	Wark et al., 2015	Australia	Community living in rural areas	17 adults	17 carers	Interviews; Thematic analysis
30	Wass et al., 2021	Norway	Employment	9 adults	None	Interviews; Thematic analysis
31	Watson et al., 2017	Australia	End of life	5 adults	33 supporters	Action research; sequential multiple case study; thematic analysis
32	Webb et al., 2020	Northen Ireland	Decision making support in health, welfare, and finances	Adults with intellectual disabilities	Adults with mental health problems	Interviews; Thematic analysis
33	Williams & Porter, 2017	UK	Social care and support	9 adults	None	Interviews; Interpretative phenomenological analysis