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## Whose voice is it anyway? Adults with intellectual disabilities and future planning: A scoping review of qualitative studies

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### ABSTRACT

**Background:** Future planning is a way of supporting people with intellectual disabilities and their families to think about their support needs as both groups age. Adults with intellectual disabilities, family members, and service providers are often involved in planning processes. However, it is unclear whose perspectives dominate in the literature and how these might vary.

**Method:** A scoping review of qualitative studies (2012–2022) was undertaken to identify which perspectives are present in research on adults with intellectual disabilities and future planning, and to examine key aspects of their future planning experience.

**Results:** The perspectives of parents and siblings predominate in the research. Those of adults with intellectual disabilities and service providers are underrepresented.

**Conclusions:** The views of adults with intellectual disabilities need to be elevated in future planning and they need to be meaningfully involved in planning processes. Focus on the experiences of service providers is likewise needed.

### ARTICLE HISTORY

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### KEYWORDS

Future planning; intellectual disabilities; parents; siblings; service providers

Due to improvements in education, health, and social care people with intellectual disabilities are now living a lifespan more like the general population (Repper-mund et al., 2020). In Australia and globally, a significant number of people with disabilities live in the family home (Australian Institute of Health and Welfare [AIHW], 2011; United Nations [UN], 2017). Consequently, life-long family caregivers are increasing, and many remain concerned about the continuity of caregiving as they age (Brennan et al., 2020). The concept of future planning – making plans for post-parental or family caregiving – has been promoted in the research literature as one approach to finding solutions to the issues of future care (Brennan et al., 2018; Deville et al., 2019; Hole et al., 2013; Leane, 2020; Lee et al., 2019; Lee & Burke, 2021; Lindahl et al., 2019; McCausland et al., 2019; Strnadová, 2019; Taggart et al., 2012; Thakkar, 2018; Walker & Hutchinson, 2019).

This future planning literature is now decades old (Bigby, 1996), and in the past 15 years, five reviews have been undertaken of this body of work (Bibby, 2012; Brennan et al., 2020; Lee & Burke, 2020; Ryan et al., 2014; Walker & Hutchinson, 2018). The reviews have provided a synthesis of the main research findings

and highlighted issues of methodological rigour. Some barriers and enablers of planning are well-documented, like the benefits of planning early (Ryan et al., 2014) and the difficulty many families face in broaching the issue of future caregiving (Bibby, 2012). Additionally, the lack of high-quality longitudinal and intervention studies about future planning has been documented (Brennan et al., 2020; Lee & Burke, 2020). However, no review has sought to understand which stakeholders are present in these studies and in what ways. This is significant, given that future planning is known to involve various people with different roles, particularly parents, siblings, and adults with intellectual disabilities whose perspectives may not necessarily align (Lee et al., 2019). Moreover, the rights approach to disability and the emphasis on choice and control in Australia and internationally create a strong imperative for future planning to be led by the preferences of adults with intellectual disabilities rather than family members (National Disability Insurance Agency [NDIA], 2023; UN, 2006). The choice is fundamental to self-determination and quality of life. However, research demonstrates that individuals with intellectual disabilities experience fewer choices and often have choices made

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for them (Stancliffe, 2020). This scoping review examines qualitative, peer-reviewed studies about future planning for adults with intellectual disabilities and the different perspectives represented in these.

## Objectives

This scoping review of the qualitative, peer-reviewed literature about adults with intellectual disabilities and future planning aimed to identify whose perspectives are represented and to what extent, and to highlight key aspects of the future planning experiences of the different groups involved. The research question was: which stakeholders have been involved in peer-reviewed studies about future planning processes and which dominate, and how does each group experience future planning? We conducted the scoping review utilising the PRISMA Extension for Scoping Reviews (PRISMA-ScR) checklist (Tricco et al., 2018). While a systematic review is appropriate for answering clinically based questions, or in identifying implications for practice, scoping reviews are well-suited to exploratory research questions, which map the available evidence in a particular area and/or identify gaps in knowledge (Munn et al., 2018).

## Methods

### Identifying relevant studies

#### Eligibility criteria, information sources, and search strategy

The inclusion criteria were that articles were published in the past 10 years and in English; qualitative or mixed methods, where the qualitative component, including its participants, were identified, and reported on separately from the quantitative findings; and focused on future planning for adults (18+) with intellectual disabilities as the biggest group. Ten years is considered standard practice for reviews (Peters et al., 2020) and qualitative findings were chosen because the review focusses on examining people's experiences (Roller & Lavrakas, 2015). Future planning could be concrete or aspirational, with its main purpose being "to ensure supports are available" for adults with intellectual disabilities in the future (Burke et al., 2018, p. 90). Studies were excluded if other disabilities were the focus, we were unable to determine the types of disabilities, or quantify the number of individuals with intellectual disabilities. The peer-reviewed literature on future planning is now decades old, and while numerous reviews have been conducted, none have sought to map the perspectives represented in this specific body of research.

Given this focus, grey literature was deemed outside the review aims (Tricco et al., 2018).

A research librarian assisted the first author with identifying data sources and mapping search strategies. Four databases were chosen and searched between October and November 2022. These were: Medline, CINAHL, Web of Science, and ProQuest. Databases were searched using a combination of MeSH, subject headings, and key words, depending on the database. Filters were also applied. Unique search strategies were piloted and then refined for each database (Arksey & O'Malley, 2005). The details of the CINAHL database search are in Table A1, Appendix A.

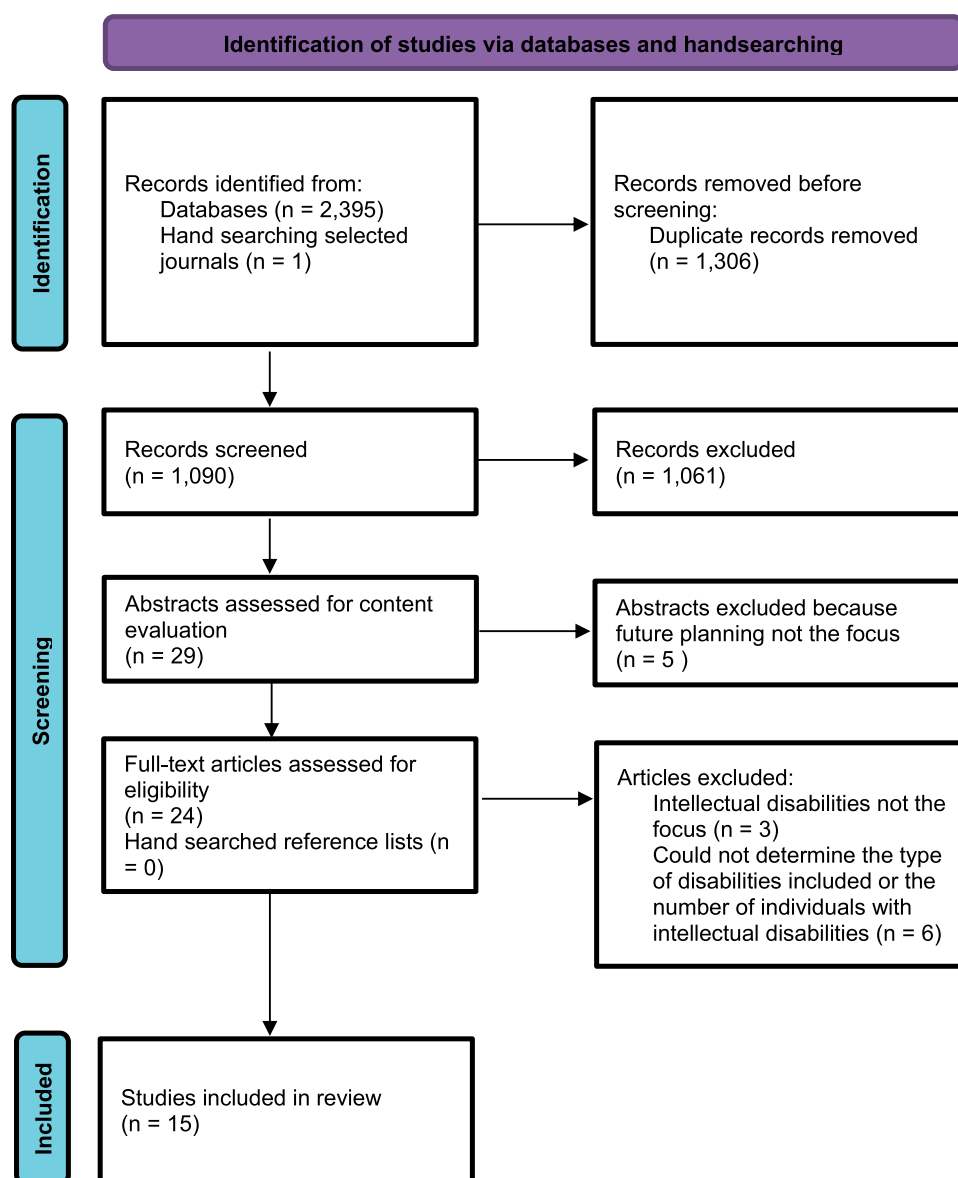
Key journals containing multiple studies on adults with disabilities and future planning were hand searched (Arksey & O'Malley, 2005). They were: *Journal of Applied Research in Intellectual Disabilities*, *British Journal of Learning Disabilities*, *Journal of Intellectual and Developmental Disability*, *Journal of Policy and Practice in Intellectual Disabilities*, *Journal of Intellectual Disabilities*, *Disability and Society*, *Intellectual and Developmental Disabilities*. The reference lists of studies selected for full-text reading were also hand searched (Arksey & O'Malley, 2005).

### Selection of sources of evidence

PRISMA guidelines were used to create a study selection flow chart, which outlines the selection process (Page et al., 2021) and is reported in Figure 1. Article titles and abstracts were initially screened and assessed according to inclusion and exclusion criteria. A three-step selection process then followed:

- (1) A thorough reading of abstracts was undertaken, and studies were excluded if future planning was not the focus.
- (2) The full text of selected studies was then read and articles were excluded if intellectual disabilities were not the majority disability; or if we were unable to ascertain this from the article. This was determined by examining the different represented disabilities and identifying which was the largest relative group.
- (3) The final articles selected focused on future planning and had the largest relative number adults (18+) with intellectual disabilities.

A form to guide the selection of sources was developed by the first two authors using Microsoft Excel and included relevant study information, such as author(s), year of publication, title and journal



**Figure 1.** Study selection flowchart with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Page et al., 2021).

information, inclusion criteria and rationale for inclusion or exclusion. These same authors undertook each step of the selection process independently. After each step, they reconvened to discuss the results and any discrepancies, including discussing the suitability of the form, which did not need to be modified. Discussion continued until consensus was reached. The Cohen's kappa inter-rater agreement for abstract screening was 0.94 and for full-text screening was 0.86.

### **Data charting process and synthesis of results**

A data charting table was created in Excel based on the recommendations by Peters et al. (2020) and following

discussion by the first two authors regarding the study aims. The table included key information about the articles and studies, such as aims/objectives; methods, including whether inclusive research practices were employed; key participant characteristics; and the main experiences of future planning identified in each study, organised by perspective, namely adults with intellectual disabilities, siblings, parents, and service providers. Only information reported by participants regarding their own experiences was used to represent their perspective. For example, where a sibling may have spoken about their view of a parent's experience, this was not included as part of the parental voice. Where findings from parents and siblings were reported together, these were charted as both siblings' and

parents' views. However, where it was indicated that a certain view was only held by siblings or only by parents these were charted separately. The same two authors who undertook study selection, engaged in data extraction and synthesis, following the same process for both stages. Namely the authors completed the data extraction and synthesis independently. Once this was completed, they met to discuss their findings. Discussion continued until consensus was reached. [Table 1](#) and [Table 3](#) contain the results of the data charting process, including the characteristics of sources of evidence, and [Table 2](#) includes the evidence synthesis.

Given that the authors chose tabular and narrative formats to present the evidence synthesis, after the initial charting was undertaken, the future planning experiences identified for each group in each study were examined again. The first author reviewed these multiple times, and key experiences were identified. These were chosen because they underscored commonalities in relation to future planning across groups while highlighting unique elements of each stakeholder experience. Once key findings had been noted by the first author, these were discussed with the second author and discussion continued until consensus was reached on all identified findings.

## Results

The discussion below compares future planning experiences and is organised according to prevalence of the participant group, beginning with parents, siblings, adults with intellectual disabilities, and lastly service providers.

### *Parents and siblings*

Eleven studies included parents as participants and reported issues from their perspectives (Brennan et al., 2018; Covelli et al., 2018; Deville et al., 2019; Hole et al., 2013; Lee et al., 2019; Lindahl et al., 2019; McCausland et al., 2019; Taggart et al., 2012; Thakkar, 2018; Walker & Hutchinson, 2019; Wilson et al., 2021). Most parents were mothers and were between 43 and 89 years old (see [Table 3](#)). Ten articles included siblings as participants and described their experiences of planning (Brennan et al., 2018; Covelli et al., 2018; Davys et al., 2015; Hole et al., 2013; Leane, 2020; Lee et al., 2019; Lee & Burke, 2021; Lindahl et al., 2019; McCausland et al., 2019; Taggart et al., 2012). Most sibling participants were sisters and were between 18 and 69 years old (see [Table 3](#)).

Concerns about the future care of their family member with intellectual disabilities remain prevalent for

parents and siblings (Brennan et al., 2018; Covelli et al., 2018; Hole et al., 2013; Leane, 2020; Taggart et al., 2012) and, for siblings, this extended to the potential caregiving responsibilities of their own children (Brennan et al., 2018; Leane, 2020). There is a lack of concrete future planning among parents and siblings (Davys et al., 2015; Deville et al., 2019; Hole et al., 2013; Walker & Hutchinson, 2019) with a limited number of studies suggesting there is variation in the extent of planning among families (Taggart et al., 2012; Thakkar, 2018). Importantly, parents (Brennan et al., 2018; Deville et al., 2019; Hole et al., 2013; Taggart et al., 2012; Wilson et al., 2021) were more likely than siblings (Brennan et al., 2018; Davys et al., 2015; Hole et al., 2013) to express concern about the impact on current plans of future changes either in the support needs of the adult with intellectual or in the wider policy and services environments. This concern may also be reflected in parents viewing appointing a caregiving successor as more important (Deville et al., 2019; Lindahl et al., 2019; Thakkar, 2018) than siblings (Lindahl et al., 2019). Finally, the number of siblings in a family also impacts future planning practices with multiple siblings creating additional complexity around future caregiving (Brennan et al., 2018; Hole et al., 2013; Leane, 2020).

### *Adults with intellectual disabilities*

Three articles included adults with intellectual disabilities and described their perspectives on future planning (Hole et al., 2013; McCausland et al., 2019; Strnadová, 2019). Adults with intellectual disabilities were aged between 30 and 69 years old, there were more females than males, and those with more complex communication and support needs were not represented (see [Table 3](#)). Only one study used inclusive research practices (Hole et al., 2013).

Similarly to parents and siblings, adults with intellectual disabilities reported being concerned about the future (Hole et al., 2013; McCausland et al., 2019; Strnadová, 2019) but with a different focus, with discussion centring on ageing parents, experiencing loneliness (Hole et al., 2013), and changes in relationship networks over time (Strnadová, 2019). This group also engaged in little future planning (Hole et al., 2013; Strnadová, 2019) and like parents and siblings identified housing as a priority area (Hole et al., 2013; McCausland et al., 2019; Strnadová, 2019). McCausland et al.'s (2019) intervention study was the only one of the three intervention studies in the review that included adults with intellectual disabilities. The authors found that person-centred practices were challenged when the future planning goals articulated by adults with intellectual disabilities

**Table 1.** Study and article characteristics.

Article number	Author(s)	Year	Article title	Country	Aims	Data collection method	Intervention study	At least one inclusive research practice*	Study participants (qualitative component)
1	Taggart, L., Truesdale-Kennedy, M., Ryan, A. & McConkey, R.	2012	Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability	Northern Ireland	Examine the support needs of ageing family carers in developing future plans for a family member with intellectual disabilities	- Postal questionnaires - Semi-structured interviews	N	N	-11 mothers -6 fathers -2 siblings
2	Hole, R. D., Stainton, T. & Wilson, L.	2013	Ageing adults with intellectual disabilities: self-advocates' and family members' perspectives about the future	Canada	Understand needs, hopes and desires of ageing adults with intellectual disabilities and their family members	- Semi-structured group and individual interviews	N	Y - Easy Read recruitment and interview material co-produced - Interview guides pilot tested by adults with intellectual disabilities and family members	-11 adults with intellectual disabilities -11 parents and siblings
3	Davys, D., Mitchell, D. & Haigh, C.	2015	Futures planning – adult sibling perspectives	England	Identify barriers to future planning among siblings	- Semi-structured interviews	N	N	-12 sisters -3 brothers
4	Brennan, D., Murphy, R., McCallion, P. & McCarron, M.	2018	“What’s going to happen when we’re gone?” Family caregiving capacity for older people with an intellectual disability in Ireland	Ireland	Examine the extent and nature of future planning of parents and siblings with an ageing family member with intellectual disabilities	- Focus groups - Semi-structured interviews	N	N	-6 parents -7 sisters -1 sister-in-law -3 brothers
5	Covelli, V., Raggi, A., Paganelli, C. & Leonardi, M.	2018	Family members' and health professionals' perspectives on future life planning of ageing people with Down syndrome: a qualitative study	Italy	Identify the future planning needs of adults with Down syndrome from a biopsychosocial perspective	- Focus groups	N	N	-5 parents -8 siblings -15 service providers
6	Thakkar, H.	2018	“It’s like me leaving a manual of me behind”: parents talk about succession planning of long-term care and support of their disabled adult children with high and complex needs	New Zealand and India	Identify what parents of children with high and complex needs report needing to help them in future planning	- Semi-structured interviews	N	N	-14 parents from New Zealand -18 parents from India -13 key informants from New Zealand -7 from India (including people with disability and government representatives)
7	Deville, J., Davies, H., Kane, R., Nelson, D. & Mansfield, P.	2019	Planning for the future: exploring the experiences of older carers of adult children with a learning disability	England	Understand the experiences of older family carers undertaking the Planning for the Future support programme	- Semi-structured interviews	Y	N	-11 mothers -2 fathers
8	Lee, C. E., Burke, M. M., & Stelter, C. R.	2019	Exploring the perspectives of parents and siblings toward future planning for individuals with intellectual and developmental disabilities	America	Understand parent and sibling perspectives on future planning	- Questionnaires - Semi-structured interviews	N	N	-10 mothers -9 sisters -1 brother

(Continued)

Table 1. Continued.

Article number	Author(s)	Year	Article title	Country	Aims	Data collection method	Intervention study	At least one inclusive research practice*	Study participants (qualitative component)
9	Lindahl, J., Stollon, N., Wu, K., Liang, A., Changalokar, S., Steinway, C., Trachtenberg, S., Coccia, A., Devaney, M. & Jan, S.	2019	Domains of planning for future long-term care of adults with intellectual and developmental disabilities: parent and siblings' perspectives	America	Evaluate future planning behaviours of caregivers of adults with severe intellectual and developmental disabilities, and create a planning framework	- Surveys - Semi-structured interviews	N	N	-14 mothers -1 father -7 sisters -3 brothers
10	McCausland, D., Brennan, D., McCallion, P., & McCarron, M.	2019	Balancing personal wishes and caring capacity in future planning for adults with an intellectual disability living with family carers	Ireland	Examine the extent of agreement of future aspirations of family caregivers and care recipients, and how this impacts on planning, from participants of My Future Care Road Map (FCRM) intervention	- Semi-structured interviews	Y	N	-12 adults with ID (9 female; 3 male) -6 mothers -5 sisters -1 brother -1 service provider supporting each family group
11	Strnadová, I.	2019	Transitions in the lives of older adults with intellectual disabilities: "Having a sense of dignity and independence"	Australia	Examine the types of transitions experienced by older adults with intellectual disabilities and identify barriers to future planning	- Semi-structured interviews	N	N	-17 adults with ID (9 female; 8 male)
12	Walker, R. & Hutchinson, C.	2019	Caregiving dynamics and futures planning among ageing parents of adult offspring with intellectual disability	Australia	Examine the caregiving dynamics and future planning of older parents of adults with intellectual disabilities	- Semi-structured interviews	N	N	-12 mothers -5 fathers
13	Leane, M.	2020	"I don't care anymore if she wants to cry through the whole conversation, because it needs to be addressed": Adult siblings' experiences of the dynamics of future care planning for brothers and sisters with developmental disability	Ireland	Understand siblings' experiences future planning	- Semi-structured interviews - Written narrative accounts	N	N	-20 sisters -5 brothers
14	Wilson, J., Tilse, C., White, B. & Rosenman, L.	2021	What is "fair and reasonable"? Norms and strategies guiding the distribution of assets by testators who have an adult child with intellectual disability	Australia	Explore the principles underlying decision-making regarding wills where a family member has intellectual disabilities	- Semi-structured interviews	N	N	-14 mothers -6 fathers
15	Lee, C. E. & Burke, M. M	2021	A pilot study of a future planning program for siblings of people with intellectual and developmental disabilities	America	Examine the feasibility and success in terms of knowledge generation of the Sibling Training for Early future Planning program (STEP) for adult siblings of individuals with intellectual and developmental disabilities	- Surveys - Semi-structured interviews	Y	N	-16 sisters -2 brothers

\*As defined by Walmsley and Johnson (2003).

**Table 2.** Synthesis of experiences of future planning according to perspective.

Author(s) article number and year	Parents	Siblings	Adults with intellectual disabilities	Parents and siblings*	Service providers
[1] Taggart et al., 2012	<ul style="list-style-type: none"> <li>- Concerns about future care</li> <li>- Variations in the extent and nature of planning</li> <li>- Need to plan early</li> <li>- Avoidance of future planning</li> <li>- Lack of support and poor housing options</li> <li>- Concern about unforeseen future changes</li> </ul>	<ul style="list-style-type: none"> <li>- Concerns about future care</li> <li>- Variations in the extent and nature of planning</li> <li>- Need to plan early</li> <li>- Avoidance of future planning</li> <li>- Lack of support and poor housing options</li> </ul>			
[2] Hole et al., 2013	<ul style="list-style-type: none"> <li>- Concerns about the future and little planning</li> <li>- The need for early planning</li> <li>- Importance of stable and secure living arrangements</li> <li>- The need for legal and financial planning</li> <li>- Role of siblings in future care</li> <li>- Parents less concerned about the future when have multiple children without disability</li> <li>- Concerns about changes over time, including to services and funding, and challenges dealing with “systems”</li> </ul>	<ul style="list-style-type: none"> <li>- Concerns about the future and little planning</li> <li>- The need for early planning</li> <li>- Importance of stable and secure living arrangements</li> <li>- The need for legal and financial planning</li> <li>- Concerns about changes over time, including to services and funding, and challenges dealing with “systems”</li> </ul>	<ul style="list-style-type: none"> <li>- A variety of future interests and hopes, including around travel, work, and retirement</li> <li>- Concern around ageing parents, suitable living arrangements and loneliness</li> <li>- Little concrete future planning occurring</li> </ul>		
[3] Davys et al., 2015		<ul style="list-style-type: none"> <li>- Concerns about the future</li> <li>- Lack of detailed future plans and variation in the extent of discussion about the future</li> <li>- Variation in parental expectations for sibling caregiving role</li> <li>- Concern over plans changing</li> <li>- Overall alignment in future wishes of parents and siblings</li> </ul>			
[4] Brennan et al., 2018	<ul style="list-style-type: none"> <li>- Concerns about future care</li> <li>- Majority without concrete plans</li> <li>- Needs of adult with intellectual disabilities will likely increase in the future</li> </ul>	<ul style="list-style-type: none"> <li>- Concerns about future care</li> <li>- Majority without concrete plans</li> <li>- Needs of adult with intellectual disabilities will likely increase in the future</li> <li>- Many siblings became inadvertent caregivers at parents’ death</li> <li>- Different circumstances of each sibling determines suitability for caregiving</li> <li>- Concerned not to pass on caregiving when they are no longer able</li> </ul>			
[5] Covelli et al., 2018	<ul style="list-style-type: none"> <li>- Mixture of thinking about the future and being concerned by it</li> </ul>	<ul style="list-style-type: none"> <li>- Mixture of thinking about the future and being concerned by it</li> <li>- Concern at not being able to take care of sibling with intellectual disabilities in the future</li> </ul>			<ul style="list-style-type: none"> <li>- Negative impact of loss and change on health</li> <li>- Institutionalisation results in a loss of independence</li> <li>- Difficulty obtaining accurate information about community dwelling adults</li> </ul>

(Continued)



Table 2. Continued.

Author(s) article number and year	Parents	Siblings	Adults with intellectual disabilities	Parents and siblings*	Service providers
[6] Thakkar, 2018	<ul style="list-style-type: none"> <li>- Variation in the extent of future planning</li> <li>- Importance of capacity building</li> <li>- Key role of informal networks</li> <li>- Need to appoint a caregiving successor and organise living arrangements</li> <li>- Financial and legal plans important</li> <li>- Creating life plans and circles of support</li> </ul>				
[7] Deville et al., 2019	<ul style="list-style-type: none"> <li>- Benefits of support tailored to parents</li> <li>- Little concrete future planning</li> <li>- Professional support assisted parents to plan</li> <li>- Importance of appointing a caregiving successor, organising living arrangements, and finalising wills</li> <li>- Concerns over long-term viability of plans, given likely changes in care needs</li> </ul>				
[8] Lee et al., 2019*	<ul style="list-style-type: none"> <li>- Uncertain about the future</li> <li>- Importance of family communication</li> <li>- Perception of limited quality programs and support for future planning</li> <li>- Financial implications of planning</li> <li>- Issues of system navigation</li> <li>- Concerns of vulnerability of family member with disabilities</li> </ul>	<ul style="list-style-type: none"> <li>- Uncertain about the future</li> <li>- Importance of family communication</li> <li>- Perception of limited quality programs and support for future planning</li> <li>- Financial implications of planning</li> <li>- Difficulty of managing different perspectives</li> <li>- Challenges in balancing own needs and life with caregiving</li> </ul>		<ul style="list-style-type: none"> <li>- Discussions of future planning lacked specificity</li> <li>- Generally agreed on future plans in relation to housing, employment and recreation</li> <li>- Identifying a caregiving successor and discussing plans with family the most agreed upon planning activities</li> </ul>	
[9] Lindahl et al., 2019	<ul style="list-style-type: none"> <li>- Seven domains of future planning identified in order of importance: housing, legal planning, identifying a primary caregiver/overseer, financial planning, day-to-day care, medical management, transport</li> </ul>	<ul style="list-style-type: none"> <li>- Seven domains of future planning identified in order of importance: housing, legal planning, identifying a primary caregiver/overseer, financial planning, day-to-day care, medical management, transport</li> </ul>			
[10] McCausland et al., 2019	<ul style="list-style-type: none"> <li>- A desire to maintain existing care arrangements and stay in the family home</li> <li>- Challenges to person-centred planning when the future wishes of the care recipient cannot be supported</li> <li>- Final plan in some cases not revealed to family member with intellectual disabilities</li> <li>- Balancing informal support against accessing formal supports</li> </ul>	<ul style="list-style-type: none"> <li>- A desire to maintain existing care arrangements and stay in the family home</li> <li>- Challenges to person-centred planning when the future wishes of the care recipient cannot be supported</li> <li>- Final plan in some cases not revealed to family member with intellectual disabilities</li> <li>- Balancing informal support against accessing formal supports</li> </ul>	<ul style="list-style-type: none"> <li>- A desire to maintain existing care arrangements and stay in the family home</li> <li>- Capacity to implement plans crucial to supporting future wishes</li> </ul>		

**Table 2.** Continued.

Author(s) article number and year	Parents	Siblings	Adults with intellectual disabilities	Parents and siblings*	Service providers
[11] Strnadová, 2019					
			<ul style="list-style-type: none"> <li>- Five main transitions for older adults with ID identified, namely in relation to work, retirement, housing, relationships, and health</li> <li>- Future plans related to work, skill development, and lifestyle</li> <li>- Some apprehension around future planning and executing these plans,</li> <li>- Concern around future planning for people living in “group homes”</li> </ul>		
[12] Walker & Hutchinson, 2019	<ul style="list-style-type: none"> <li>- Parents continue to play an active caregiving role even if the adult with intellectual disabilities has moved out of the family home</li> <li>- Lack of trust in service providers</li> <li>- Benefits and costs of ongoing caregiving role</li> <li>- An awareness of the need to plan</li> <li>- Lack of concrete plans</li> </ul>				
[13] Leane, 2020		<ul style="list-style-type: none"> <li>- Future care needs of sibling ongoing source of concern</li> <li>- Future planning discussions between parents and siblings limited</li> <li>- Plans mostly in relation to living arrangements, finances, care and support networks and respite services</li> <li>- Mothers identified as most influential in shaping future planning discussions a</li> <li>- Concerns about the intergenerational transfer of caregiving</li> <li>- Issues of unspoken expectations</li> <li>- Complications around guardianship arrangements for siblings</li> <li>- In families with multiple siblings usually “most involved sibling” role and more complicated dynamics</li> </ul>			
[14] Wilson et al., 2021	<ul style="list-style-type: none"> <li>- Difficulty with planning because of likely changes in personal circumstances and wider policy, legal and systems environments</li> <li>- Diversity among parents regarding division of assets between children with and without disability but all guided by wanting to preserve family harmony and access to government support</li> </ul>				

**Table 2.** Continued.

Author(s) article number and year	Parents	Siblings	Adults with intellectual disabilities	Parents and siblings*	Service providers
	<ul style="list-style-type: none"> <li>- Complexity of guardianship arrangements</li> <li>- Housing, financial, and legal plans the most common</li> <li>- Family discussions lacked detail</li> <li>- Difficulty and expense of getting professional advice</li> </ul>				
[15] Lee & Burke, 2021		<ul style="list-style-type: none"> <li>- Increased ability to initiate family discussions about planning by having a structured guide</li> <li>- Increased level of peer support through participation in the program</li> <li>- Siblings felt more empowered as advocates</li> <li>- Increased understanding of adult disability services</li> </ul>			

\*Lee et al. (2019) discuss both parent/sibling dyad results and individual findings from each group.

could not be met. In these cases, family and/or service providers tended to explore alternatives without input from the adult with intellectual disabilities (McCausland et al., 2019).

### Service providers

Three studies involved service providers (Covelli et al., 2018; McCausland et al., 2019; Thakkar, 2018), and none of these focused exclusively on the experiences of this group. Only Covelli et al. (2018) reported on their views directly, albeit in a limited fashion. The service providers in Covelli et al.'s (2018) study were mainly female and aged between 38 and 64 years (see Table 3). They reported a unique perspective on future caregiving. They identified a perceived reduction in independence in adults with intellectual disabilities who had been institutionalised. Further, they highlighted the importance of maintaining continuity of routine and minimising sudden changes for the health and well-being of this cohort.

### Discussion

As has been articulated in previous research and confirmed in this review, adults with intellectual disabilities remain underrepresented in the research literature and those with more complex support and communication needs are absent as participants. This finding points to a significant gap in the current understanding of the future planning and caregiving needs of an important population. A better understanding of these considerations will support the development of person-centred, rights-based interventions. Further, there is limited use of inclusive research approaches. Again, this is an area that requires attention, given the centrality and importance of the “Nothing about us without us” disability rights movement and its emphasis on inclusive research practices (O'Brien et al., 2022).

Brennan et al. (2018), Hole et al. (2013), and Leane (2020) all highlight that the number of siblings in a family can impact future planning practices. These findings are not new and were highlighted by both

Davys et al. (2011) and Burke et al.'s (2018) reviews. The issue of multiple siblings in a family and its connection to future planning suggests that a greater focus on the family as a system, and concepts such as family quality of life may be beneficial in future planning research and interventions (Zuna et al., 2010)

A particular aspect of future planning for parents is nominating a caregiving successor(s). The difficulty in doing this, for example, because of family dynamics, can impede the planning process (Deville et al., 2019; Lee et al., 2019; Lindahl et al., 2019; Thakkar, 2018). Further, parents in particular reported concerns about not being able to plan for contingencies and changes in circumstance, such as increased support needs (Davys et al., 2015; Deville et al., 2019; Hole et al., 2013; Taggart et al., 2012; Wilson et al., 2021). Additionally, there remains a lack of concrete future planning generally, despite evidence suggesting that it is important in ensuring adult with intellectual disabilities' support into the future (Brennan et al., 2018; Deville et al., 2019; Taggart et al., 2012; Walker & Hutchinson, 2019). These findings suggest that the concept of future planning itself may require further examination. This assertion is not new. Indeed, a greater focus on supporting the identification of a caregiving successor(s) in families has already been identified as a way of addressing some of the limitations of more traditional approaches to future planning, such as a lack of flexibility (Bibby, 2012; Bigby, 2000; Ryan et al., 2014; Taggart et al., 2012).

The lack of inclusion of service providers as participants is a significant finding. For people without family support, paid services are often the only source of assistance for future planning and their key role in future planning practices for families has already been noted by Bibby (2012). Interestingly, Walker and Hutchinson (2019) indicate that among the adults with intellectual disabilities living out of home in their study, none were approached by service providers to engage in future planning activities. Given the important role of service providers and the lack of evidence regarding their experiences of future planning, additional research with these stakeholders is of pressing concern.

**Table 3.** Key demographic characteristics of study participants (qualitative component)\*.

Sample characteristic	Adults with intellectual disabilities	Parents	Siblings	Service providers	Article number
Age	30–69	43–89	18–69	38–64	[3]; [5]; [7]; [8]; [9]; [10]; [11]; [12]; [13]; [14]; [15]
Gender	18 female; 11 male	78 mothers; 20 fathers	77 sisters; 18 brothers	12 female; 3 male	[1]; [3]; [4]; [5]; [7]; [8]; [9]; [10]; [11]; [12]; [13]; [14]; [15]
Level of Intellectual disability**	1 mild 16 mild to moderate 3 moderate 3 moderate to severe	-	-	-	[2]; [10]

\*Where the information was reported.

\*\*Included as described in the two articles that documented this.

## Strengths and limitations

The current scoping review provides important insights into the different perspectives currently represented in the peer-reviewed, qualitative literature on future planning. It particularly highlights the lack of representation of adults with intellectual disabilities and more specifically the total absence of those with more complex support and communication needs as participants. The scope of the current review was narrow, excluding quantitative studies, reviews, and grey literature. Additionally, in only choosing articles with future planning as the focus, studies that included this as a small part of larger discussions around future caregiving were excluded.

## Conclusion

The qualitative literature on adults with intellectual disabilities and future planning continues to evolve. However, there are several long-standing issues that are yet to be addressed, including the lack of meaningful inclusion of adults with intellectual disabilities, the absence of individuals with complex communication and support needs, and limited engagement with inclusive research practices. Further, despite some evidence that suggests that paid services are important in future planning practices, this perspective remains virtually absent. Moreover, calls to critically examine the concept of future planning have gone unanswered with a consequent lack of reflexivity in the literature and an absence of alternatives for adults with intellectual disabilities and their families to consider. These findings suggest a clear way forward for the research literature regarding future planning, with a greater focus on inclusivity and reflexivity and more attention to the nuanced experiences of the different stakeholders involved in future planning activities.

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## References

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social*

*Research Methodology*, 8(1), 19–32. <https://doi.org/10.1080/1364557032000119616>

Australian Institute of Health and Welfare [AIHW]. (2011). *Disability support services 2009-2010: Report on Services Provided Under the National Disability Agreement*. <https://www.aihw.gov.au/reports/disability/disability-support-services-2009-10/contents/summary>.

Bibby, R. (2012). "I hope he goes first": Exploring determinants of engagement in future planning for adults with a learning disability living with ageing parents. What are the issues? A literature review. *British Journal of Learning Disabilities*, 41(2), 94–105. <https://doi.org/10.1111/j.1468-3156.2012.00727.x>

Bigby, C. (1996). Transferring responsibility: The nature and effectiveness of parental planning for the future of adults with intellectual disability who have remained at home until mid-life. *Journal of Intellectual & Developmental Disability*, 21(4), 295–312. <https://doi.org/10.1080/13668259600033211>

Bigby, C. (2000). *Moving on without parents. Planning, transitions and sources of support for middle-aged and older adults with intellectual disability*. Paul H. Brookes Publishing Co.

Brennan, D., McCausland, D., O'Donovan, M. A., Eustace-Cook, J., McCallion, P., & McCarron, M. (2020). Approaches to and outcomes of future planning for family carers of adults with an intellectual disability: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, 33(6), 1221–1233. <https://doi.org/10.1111/jar.12742>

Brennan, D., Murphy, R., McCallion, P., & McCarron, M. (2018). "What's going to happen when we're gone?" Family caregiving capacity for older people with an intellectual disability in Ireland. *Journal of Applied Research in Intellectual Disabilities*, 31(2), 226–235. <https://doi.org/10.1111/jar.12379>

Burke, M., Arnold, C., & Owen, A. (2018). Identifying the correlates and barriers of future planning among parents of individuals with intellectual and developmental disabilities. *Intellectual & Developmental Disabilities*, 56(2), 90–100. <https://doi.org/10.1352/1934-9556-56.2.90>

Covelli, V., Raggi, A., Paganelli, C., & Leonardi, M. (2018). Family members and health professionals' perspectives on future life planning of ageing people with Down syndrome: A qualitative study. *Disability & Rehabilitation*, 40(24), 2867–2874. <https://doi.org/10.1080/09638288.2017.1362595>

Davys, D., Mitchell, D., & Haigh, C. (2011). Adult sibling experience, roles, relationships and future concerns – A review of the literature in learning disabilities. *Journal of Clinical Nursing*, 20(19-20), 2837–2853. <https://doi.org/10.1111/j.1365-2702.2010.03530.x>

Davys, D., Mitchell, D., & Haigh, C. (2015). Futures planning – Adult sibling perspectives. *British Journal of Learning Disabilities*, 43(3), 219–226. <https://doi.org/10.1111/bld.12099>

Deville, J., Davies, H., Kane, R., Nelson, D., & Mansfield, P. (2019). Planning for the future: Exploring the experiences of older carers of adult children with a learning disability. *British Journal of Learning Disabilities*, 47(3), 208–214. <https://doi.org/10.1111/bld.12279>

Hole, R. D., Stainton, T., & Wilson, L. (2013). Ageing adults with intellectual disabilities: Self-advocates' and family

- members' perspectives about the future. *Australian Social Work*, 66(4), 571–589. <https://doi.org/10.1080/0312407X.2012.689307>
- Leane, M. (2020). “I don't care anymore is she wants to cry through the whole conversation, because it needs to be addressed”: Adult siblings' experiences of the dynamics of future care planning for brothers and sisters with a developmental disability. *Journal of Applied Research in Intellectual Disabilities*, 33(5), 950–961. <https://doi.org/10.1111/jar.12716>
- Lee, C. E., & Burke, M. M. (2020). Future planning among families of individuals with intellectual and developmental disabilities: A systematic review. *Journal of Policy and Practice in Intellectual Disabilities*, 17(2), 94–107. <https://doi.org/10.1111/jppi.12324>
- Lee, C. E., & Burke, M. M. (2021). A pilot study of a future planning program for siblings of people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 59(1), 70–83. <https://doi.org/10.1352/1934-9556-59.1.70>
- Lee, C. E., Burke, M. M., & Stelter, C. R. (2019). Exploring the perspectives of parents and siblings toward future planning for individuals with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 57(3), 198–211. <https://doi.org/10.1352/1934-9556-57.3.198>
- Lindahl, J., Stollon, N., Wu, K., Liang, A., Changolkar, S., Steinway, C., Trachtenberg, S., Coccia, A., Devaney, M., & Jan, S. (2019). Domains of planning for future long-term care of adults with intellectual and developmental disabilities: Parent and sibling perspectives. *Journal of Applied Research in Intellectual Disabilities*, 32(5), 1103–1115. <https://doi.org/10.1111/jar.12600>
- McCausland, D., McCallion, P., Brennan, D., & McCarron, M. (2019). Balancing personal wishes and caring capacity in future planning for adults with an intellectual disability living with family carers. *Journal of Intellectual Disabilities*, 23(3), 413–431. <https://doi.org/10.1177/1744629519872658>
- Munn, Z., Peters, M. D. J., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*, 18(1), 143. <https://doi.org/10.1186/s12874-018-0611-x>
- National Disability Insurance Agency. (2023, April). *NDIS supported decision making policy*. National Disability Insurance Scheme. <https://www.ndis.gov.au/about-us/policies/supported-decision-making-policy>.
- O'Brien, P., García Iriarte, E., Mc Conkey, R., Butler, S., & O'Brien, B. (2022). Inclusive research and intellectual disabilities: Moving forward on a road less well-travelled. *Social Sciences*, 11(10), 483. <https://doi.org/10.3390/socsci11100483>
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffman, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., ... Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, 372, n71. <https://doi.org/10.1136/bmj.n71>
- Peters, M. D. J., Godfrey, C., McInerney, P., Munn, Z., Tricco, A. C., & Khalil, H. (2020). Chapter 11: Scoping reviews (2020 version). In E. Aromataris, & Z. Munn (Eds.), *JBI manual for evidence synthesis* (pp. 406–451). Joanna Briggs Institute.
- Reppermund, S., Srasuebku, P., Dean, K., & Trollor, J. N. (2020). Factors associated with death in people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 33(3), 420–429. <https://doi.org/10.1111/jar.12684>
- Roller, M. R., & Lavrakas, P. J. (2015). *Applied qualitative research design: A total quality framework approach*. The Guilford Press.
- Ryan, A., Taggart, L., Truesdale-Kennedy, M., & Slevin, E. (2014). Issues in caregiving for older people with intellectual disabilities and their ageing family carers: A review and commentary. *International Journal of Older People Nursing*, 9(3), 217–226. <https://doi.org/10.1111/opn.12021>
- Stancliffe, R. J. (2020). Choice availability and people with intellectual disability. In R. J. Stancliffe, M. L. Wehmeyer, K. A. Shogren, & B. H. Abery (Eds.), *Choice, preference, and disability* (pp. 3–26). Springer.
- Strnadová, I. (2019). Transitions in the lives of older adults with intellectual disabilities: “Having a sense of dignity and independence”. *Journal of Policy and Practice in Intellectual Disabilities*, 16(1), 58–66. <https://doi.org/10.1111/jppi.12273>
- Taggart, L., Truesdale-Kennedy, M., Ryan, A., & McConkey, R. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities*, 16(3), 217–234. <https://doi.org/10.1177/1744629512456465>
- Thakkar, H. (2018). “It's like me leaving a manual of me behind”: Parents talk about succession planning of long-term care and support of their disabled adult children with high and complex needs. *Aotearoa New Zealand Social Work*, 30(2), 3–15. <https://doi.org/10.11157/anzswj-vol30iss2id506>
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garrity, C., ... Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467–473. <https://doi.org/10.7326/M18-0850>
- United Nations. (2006). *Convention on the rights of persons with disabilities (CRPD)*. <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd>.
- United Nations. (2017). *Adequate housing as a component of the right to an adequate standard of living, and the right to non-discrimination in this context*. <https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/212/20/PDF/N1721220.pdf?OpenElement>.
- Walker, R., & Hutchinson, C. (2018). Planning for the future among older parents of adult offspring with intellectual disability living at home and in the community: A systematic review of qualitative studies. *Journal of Intellectual & Developmental Disability*, 43(4), 453–462. <https://doi.org/10.3109/13668250.2017.1310823>
- Walker, R., & Hutchinson, C. (2019). Care-giving dynamics and futures planning among ageing parents of adult offspring with intellectual disability. *Ageing & Society*, 39(7), 1512–1527. <https://doi.org/10.1017/S0144686X18000144>

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures*. Jessica Kingsley Publishers.

Wilson, J., Tilse, C., White, B., & Rosenman, L. (2021). What is “fair and reasonable”? Norms and strategies guiding the distribution of assets by testators who have an adult child with intellectual disability. *Journal of Intellectual & Developmental Disability*, 46(2), 175–185. <https://doi.org/10.3109/13668250.2020.1765997>

Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X., & Xu, S. (2010). Theorizing about family quality of life. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities. Social indicators research series 41* (pp. 241–278). Springer Science + Business Media.

## Appendix

Table A1. Search strategy for CINAHL.

Database	Search terms	Filters	Results
CINAHL	1. MH Intellectual disability + (Cockayne Syndrome; Coffin-Siris Syndrome; Cri-Du-Chat Syndrome; De Bary Syndrome; De Lange Syndrome; Down Syndrome; Gaucher Disease; Kinky Hair Syndrome; Kleefstra Syndrome; Intellectual Disability, X-Linked;	2012–2023English	393

(Continued)

## Continued.

Database	Search terms	Filters	Results
	Phenylketonuria; Prader-Willi Syndrome; Rett Syndrome; Rubinstein-Taybi Syndrome; Schinzel-Giedon Syndrome; WAGR Syndrome; Williams Syndrome)/		
	2. MH Intellectual disability, X-Linked + (Adrenoleukodystrophy; Coffin-Lowry Syndrome; Fragile X Syndrome; Kinky Hair Syndrome; Mucopolysaccharidosis II; Rett Syndrome)/		
	3. MH Learning disorders + (Dyscalculia; Dyslexia)/		
	4. MH Developmental disabilities/		
	5. MH persons with mental disabilities/		
	6. MH autistic disorder/		
	7. MH Asperger syndrome/		
	8. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7/		
	9. futur*/		
	10. plan*/		
	11. succession/		
	12. estate/		
	13. "person-cent**"/		
	14. "person cent**"/		
	15. 13 OR 14/		
	16. 9 AND 10/		
	17. 10 AND 11/		
	18. 10 AND 12/		
	19. 10 AND 15/		
	20. 16 OR 17 OR 18 OR 19/		
	21. 8 AND 20.		