


ORIGINAL ARTICLE

Domains of planning for future long-term care of adults with intellectual and developmental disabilities: Parent and sibling perspectives

Jane Lindahl¹  | Natalie Stollon² | Katherine Wu³ | Angela Liang³ |
Sujatha Changolkar⁴ | Caren Steinway¹ | Symme Trachtenberg² | Audrey Coccia⁵ |
Maureen Devaney⁵ | Sophia Jan¹

¹Division of General Pediatrics, Steven & Alexandra Cohen Children's Medical Center of Northwell Health, New Hyde Park, New York

²Children's Hospital of Philadelphia, Philadelphia, Pennsylvania

³PolicyLab, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania

⁴Division of General Internal Medicine, Penn Medicine Nudge Unit, Perelman School of Medicine, Philadelphia, Pennsylvania

⁵Vision For Equality, Inc., Philadelphia, Pennsylvania

Correspondence

Jane Lindahl, Department of General Pediatrics, Steven and Alexandra Cohen Children's Medical Center, Northwell Health, New Hyde Park, NY.
Email: jlindahl@northwell.edu

Funding information

Oscar G. and Elsa S. Mayer Family Foundation

Abstract

Background: Research shows that adults with intellectual and developmental disabilities (IDD) increasingly outlive caregivers, who often struggle to plan for the future and have little support and knowledge surrounding long-term care planning.

Methods: The study team conducted interviews with parents and siblings of adults with IDD and performed qualitative coding using a modified grounded theory to explore domains of future planning and identify barriers and facilitators.

Results: Themes from the interviews revealed seven major domains of future planning that should be considered by caregivers of adults with IDD. These domains are housing, legal planning, identification of primary caregiver(s), financial planning, day-to-day care, medical management and transportation. Approaches to planning within each domain varied greatly.

Conclusions: The study team identified the domain of "identification of primary caregiver(s)" as potentially the most important step for caregivers when planning for the future, but also observed that the domains identified are significantly interrelated and should be considered together.

KEYWORDS

caregivers, disability, long-term care, planning, transition

1 | INTRODUCTION

As advances in health care over the past century have greatly increased the life expectancy for adults with intellectual and developmental disabilities (IDD) (Brennan, Murphy, McCallion, & McCarron, 2018), the possibility of these adults living longer than their parents has become much more common. Thus, the need for the families of these adults to plan for long-term care has emerged. These

caregivers, who are typically ageing parents, take on the non-normative role of caring for their children from birth and childhood all the way through adulthood. In some cases, that parenting role can span up to seven decades (Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2014). Research has shown that many parents and siblings feel anxiety about the long-term care plans for their adult relative with IDD (Davys & Haigh, 2007; Davys, Mitchell, & Haigh, 2010; Freedman, Krauss, & Seltzer, 1997; Weeks, Nilsson, Bryanton, & Kozma, 2009).

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2019 The Authors *Journal of Applied Research in Intellectual Disabilities* Published by John Wiley & Sons Ltd

Previous research has found that caregivers in this group are likely to be socially and economically disadvantaged and at greater risk than most to develop serious health issues (Black & McKendrick, 2010; McConkey, 2005; Ryan et al., 2014). In another study, a survey of lone caregivers reported a wide array of health issues and high levels of anxiety relating to their caregiving responsibilities (Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012). This is a group that is already structurally disadvantaged, marginalized and experiencing anxiety, thus typically faces difficulty in creating long-term plans for a child with IDD. Further, studies have found that many families only have an emergency plan in place, not a comprehensive long-term plan and families show no clear evidence of “succession or future planning” (Black & McKendrick, 2010). Taggart et al. (2012) further distinguish between “definitive” plans for the person with IDD, that included decisions made together with the individual with IDD and other family members, and “aspirational plans,” in which caregivers had an idea of what they would *like* to happen in the future but had not discussed anything definitively (Taggart et al., 2012). Bigby (2000) asserts that there is international evidence showing that there is a lack of long-term care planning and no clear designation of who will provide long-term care after parents are unable to do so in many families caring for an individual with IDD. One study asked 62 older caregivers about their perspectives on planning for the future and found that 55% were not ready or unwilling to think about making plans for the future of their family member with IDD (Bowey & McGlaughlin, 2007).

The combined knowledge that adults with IDD increasingly outlive their caregivers and that those caregivers seldom make definitive plans for long-term care of their child or sibling with IDD suggests a need for increased understanding of what is needed to encourage comprehensive long-term planning and how to better support caregivers in future planning. While extensive research exists demonstrating this need, few studies have examined comprehensively what domains of planning need to be considered by ageing caregivers and siblings of adults with IDD and what barriers and facilitators to planning exist within different domains. This study aims to fill some of those gaps in knowledge and create a foundation for future studies and programmes to help support the caregivers of adults with IDD in planning for the future. To do this, the study team sought to evaluate the nature of future planning among caregivers of adults with severe intellectual and developmental disabilities and create a framework for the type of planning that should happen as well as investigate any themes within that framework, such as barriers and facilitators of future planning.

2 | METHODS

2.1 | Participant recruitment

The study team recruited a convenience sample of participants by distributing flyers via email listservs managed by community agencies that serve individuals with IDD, as well as through support

organizations for parents and siblings, including from an urban intellectual disability social service agency. The study team also distributed flyers advertising the study in clinics at Children's Hospital of Philadelphia and Penn Medicine, both of which are independent, free-standing institutions, located in a large urban city. Participants contacted the study team by phone or email if they were interested in participating. Additionally, the study team used a snowball sampling method for recruiting within families to ensure recruitment of both parents and siblings. If one member of the family participated in the study, following the interview, the study team asked if they had other family members who might be eligible and interested.

Eligible participants were parents and siblings of adults with IDD who were 18 years or older and still living in family homes. Parents and siblings were asked about current family caregiving arrangements, information on state and Medicaid disability funding such as through “waiver programs,” caregiver health, prior examples of family crisis and future family caregiving arrangement and planning. In addition, all participating parents and siblings of individuals with IDD were asked to complete surveys about overall parental health, caregiver burden, maladaptive or problem behaviours and functional adaptability.

2.2 | Data collection

The study team conducted semi-structured qualitative interviews with 15 parents and 10 siblings of adults with IDD. Interviews were conducted over the phone, in-person in the participant's home, or at Children's Hospital of Philadelphia (CHOP). Interviews were conducted from April 2016 to August 2016.

The interviews included questions about the individual with IDD and their current living arrangements, as well as short and long-term plans for future caregiving. Questions used to guide interviews with parents and siblings are shown in Tables 1 and 2. For consistency, all interviews were conducted by the same author (NS), who is trained in qualitative interviewing. Interviews lasted between 30 and 60 min. Following the interview, participants completed surveys, either online or by phone. The surveys included: The Zarit Burden Interview (Zarit, Orr, & Zarit, 1985); PROMIS Global Health Measure (Hays, Bjorner, Revicki, Spritzer, & Cella, 2009); Scales of Independent Behavior-Revised, Adaptive Behavior Section (Bruininks, Woodcock, Weatherman, & Hill, 1996); Waisman Activities of Daily Living Scale (Maenner et al., 2013); and demographic information of the family participant and the adult with IDD. Participants were given the option to complete these surveys over the phone directly after completion of the interview or to complete the surveys online. For participants who completed online surveys, the interviewer emailed a link to the participants after they got off the phone. The participant then completed the survey online at a time that was convenient for them. Survey data were collected and managed using REDCap electronic data capture tools hosted at Children's Hospital of Philadelphia. REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies (Harris et al., 2009).

TABLE 1 Parent interview questions

Current family caregiving arrangement questions
Tell me a little about your son or daughter who has an intellectual or developmental disability
Where does s/he currently live?
Who lives in the home with you?
Who are the main people who help you support [son/daughter's name], and what are their roles?
If not mentioned, probe for people outside the home, including siblings, other family members and friends
If not mentioned, probe for formal support individuals, Paid or unpaid, formal or informal
Tell me a little about your family
What role does each family member play in the care or support of [child's name], if any?
If sibling is now the primary caregiver: Please describe how you became [child's name's] primary caregiver
Are you a caregiver for another family member (probe for grandparents)?
Waiver information
Is your son/daughter on a waiver? Which one? Tell me about any services that your son or daughter currently uses that is paid by the waiver
What other activities does your son or daughter engage in that is not related to or paid for by the waiver?
Caregiving and health
Do any of the family members have health problems? How does this impact the care of [sibling's name]?
Prior examples of family crisis
Tell me about the last time you were so sick that you were unable to take care of [child's name]
Was there ever a time when you wished you had planned for a different living arrangement with you son/daughter? Was there ever a time that you were so stressed that you felt as if you were unable to adequately support or care for [name]? Please describe the situation
Was there anyone else who supported you? Please tell me more
Who or what did you need to help you at the time?
Future family caregiving arrangement/planning
Who helps [name] with his/her day to day activities?
Is this a routine that you expect will continue for the next 5 years?
If no, how will it change?
What supports will you need?
Is this a routine that you expect will continue for the next 10 years?
If no, how will it change?
What supports will you need?
If yes, how will you sustain this routine?
Are you a caregiver for other family members?
If not already addressed, what is the role for [name]'s sibling? What are the roles of [name]'s other family members?
Is there anything else you would like to mention that has not already been discussed earlier?

TABLE 2 Sibling interview questions

Current family caregiving arrangement questions
Tell me a little about your brother or sister who has an intellectual or developmental disability
Can you describe where s/he lives? Does he or she live with you?
Who are the main people who help support [your sibling's name], and what are their roles?
If not mentioned, probe for people outside the home, including siblings, other family members and friends
If not mentioned, probe for formal support individuals, Paid or unpaid, formal or informal
Tell me a little about your family
What role does each family member play in the care or support of [sibling's name], if any?
If sibling is now the primary caregiver: Please describe how you became [sibling's name's] primary caregiver
Caregiving and health questions
Do any of the family members have health problems? How does this impact the care of [sibling's name]?
What is your role?
Do you think this arrangement is sustainable? Tell me more.
Are you a caregiver for other family members?
Prior examples of family crisis
Tell me about the last time [primary caregiver] was so sick that s/he was unable to take care of [sibling's name]
Was there ever a time when you wished you had planned for a different living arrangement with your [brother/sister]? Was there ever a time that you were so stressed that you felt as if you were unable to adequately support or care for [name]? Please describe the situation.
Was there anyone else who supported you? Please tell me more.
Who or what did you need to help you at the time?
Future family caregiving arrangement/planning
How will this change when [the sibling's primary caregiver] is unable to continue his/her care of [sibling]?
Do you expect your role to change in the next 5 years?
Do you expect your role to change in the next 10 years?
What kind of supports would you need to be successful in the next 5 years?
What kind of supports would you need to be successful in the next 10 years?
People who already live in residential services
If adult child does not live at home: Can you tell me about when [name] moved to [living situation]. What was helpful at that time? What was challenging?
Is there anything else you would like to mention that has not already been discussed earlier?

2.3 | Data analysis

Interviews were recorded and transcribed verbatim by a HIPAA-compliant transcription company. Upon transcription, all identifying information was removed from transcripts.

TABLE 3 Demographic & clinical characteristics of family caregiver participants

	Sibling (n = 10)	Parent (n = 15)
Male, n (%)	3 (30)	1 (7)
Race, n (%)		
White	10 (100)	10 (67)
Black or African American	0 (0)	3 (20)
Mean age (range)	29.0 (18–44)	59.9 (43–70)
State of residence, n (%)		
Pennsylvania	7 (70)	15 (100)
Other	2 (20)	0 (0)
Education level, n (%)		
HS diploma or GED	0 (0)	2 (13)
Associate's or college	4 (40)	10 (67)
Graduate/prof degree	6 (60)	3 (20)
Yearly household income, n (%)		
Less than \$34,999	2 (20)	2 (13)
\$35,000 to \$49,999	2 (20)	2 (13)
\$50,000 to \$74,999	2 (20)	3 (20)
>\$75,000	4 (40)	9 (60)
Zarit burden interview, mean		
Level of burden range 0–88	15.4	17.3
PROMIS global health, mean		
Physical health, range 0–15	12.4	12.87
Emotional health, range 0–20	14.6	13.4

The study team used a modified grounded theory (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990) approach to identify interview themes. This meant that authors had some initial themes they were coding for, but allowed additional themes and codes to emerge from the data during the iterative coding process. Some a priori codes were initially used based on literature indicating that most families do not engage in future planning until a time of crisis (Black & McKendrick, 2010), and the interviews sought to examine how families react to crisis situations and what qualities made caregivers more or less likely to plan for the future in order to identify possible areas where interventions might facilitate more comprehensive and pre-emptive planning. A priori codes included: "Barriers to future planning," "Communication of future planning," "Crisis and how it was handled," "Fears and concerns," "Hopes and dreams," "Motivators, triggers, facilitators" and "Perceived urgency." While coding for barriers and facilitators, unique categories of drivers of long-term care planning emerged from the data as well. The process was iterative, and all members of the study team were involved. The interview transcripts were analysed in NVivo 11 (NVivo Qualitative Data Analysis Software, 2015) by two trained research assistants (KW, AL). Any

disagreements were discussed with a third author (NS or SJ) until a consensus was reached.

Regarding the experience of the authors who conducted the qualitative analysis, Natalie Stollon (NS) has been working with individuals with IDD and their families for 15 years, first as support staff and currently as a social worker at a children's hospital. In both these roles, this author may be more likely to meet families who are seeking support (i.e. who may be in crisis), and therefore may have had preconceived notions that crises may act as a catalyst to future planning. Katherine Wu (KW) has been working with individuals with IDD and their families for 3 years as a community health worker at Children's Hospital of Philadelphia. In this role, this author may meet patients and families who are in the process of transitioning from paediatric to adult care, and may have preconceived notions about the transition-related and IDD-related topics that families choose to discuss in a clinical setting as well as the emotions families may express during the process of transition to adulthood. Dr. Sophia Jan (SJ) was trained in Medicine and Pediatrics and has been working with young adults with complex care needs, including IDD, as they transition from paediatric to adult care throughout her career as a physician and researcher. She also has a sibling with IDD herself, thus her personal background in the field may have influenced her preconceived notions about IDD and transition-related care, and she has a personal understanding of the emotions and lived experiences of families of someone with IDD. Angela Liang (AL) was introduced to the field of intellectual disabilities and long-term care planning through this research and had limited prior knowledge or preconceptions when conducting this analysis.

The survey data were analysed using summary statistics in order to describe our sample.

2.4 | Human subjects research

This research study was granted exemption from Children's Hospital of Philadelphia and University of Pennsylvania Institutional Review Boards (IRB). It was approved by the City of Philadelphia IRB.

3 | RESULTS

3.1 | Sample

The study team conducted interviews with 15 parents and 10 siblings of adults with IDD. Five of these were with parent-sibling dyads. The mean age of parents in our sample was 59.9 (43–70), and of siblings was 29.0 (18–44). Both parents (67%) and siblings (100%) were predominantly White. Additionally, 60% of parents and 40% of siblings had a yearly household income of over \$75,000 (See Table 3). Parents and siblings both reported overall poor health, with PROMIS Global Health Measure score means for emotional health and physical health in both groups two standard deviations below the general population (Hays et al., 2009). Caregiver burden, as reported on the Zarit Burden Interview, was found to be relatively low, with reported mean burden scores of 15.4 and 17.3 for parents and siblings respectively (on a scale from 0 to 88 with 88 being the highest level

TABLE 4 Demographic and clinical characteristics of dependent adults with intellectual and developmental disabilities (IDD)

Male, <i>n</i> (%)	6 (40%)
Race, <i>n</i> (%)	
White	10 (67%)
Black or African American	3 (20%)
Mean age (Range)	28.5 (18–41)
Medicaid waiver status, <i>n</i> (%)	
Consolidated waiver	7 (47%)
OBRA waiver	1 (7%)
Person/family directed	5 (44%)
None	2 (13%)
Waisman activities of daily living, 0 = does not do at all, 1 = does with assistance, 2 = does independently	
Basic ADL, mean	1.533
Instrumental ADL, mean	0.808
≥1 Problem behaviour, <i>n</i> (%)	11 (73%)

of burden; Zarit et al., 1985). The adults with IDD ($N = 15$) ranged in age from 18 to 41 years, with a mean age of 28.5 years. A total of 20 families of adults with IDD were involved in this study, most of whom had both parent caregivers and siblings involved in the study. However, five of the adults with IDD only had a sibling caregiver involved in the study. Only parent caregivers completed the surveys about their child with IDD, in order to avoid discrepancies between parent and sibling caregivers, thus the survey data only reflect the 15 adults with IDD who had a parent involved in the study. The adults with IDD had a mean Waisman score of 1.045, meaning that on average the adults with IDD reported on in this study required assistance for most activities of daily living. Additionally, based on responses to the Problem Behavior Section of the Scales of Independent Behavior (Revised) Tool, 55% of adults with IDD in this study exhibited at least one problem behaviour, which could include: being hurtful to oneself or others; being destructive to property; or having socially offensive behaviour (Table 4). See Tables 3 and 4 for additional demographic and functional information regarding the study sample.

3.2 | Framework of long-term care planning activities

Multiple themes in the data emerged through qualitative analysis. Based on those themes, a framework was developed. The framework consists of seven major domains of planning. Within some domains, multiple subcategories emerged, revealing various approaches and planning activities within each of the domains. The domains, in the order of how often they were discussed by the parents and siblings who were interviewed, are as follows: housing; legal planning; identification of a primary caregiver or overseer; financial planning; day-to-day care; medical management; and transportation. Tables 5–11 display each domain of this framework with subcategories and illustrative interview quotes included.

TABLE 5 Housing

Group home	Speaker
“The ultimate plan at this point [...] the thinking is that eventually when I'm no longer here, that [Individual with IDD] and [Individual with IDD] would be able to live together in one of these group homes.”	Parent, Female
“Oh, we always knew that we wanted her to be in a group home. I didn't want her brothers to have to worry about placement or anything for her as we got older.”	Parent, Female
“There's a group of us that all have kids with disabilities, varying disabilities, and we've discussed having – making a – buying a house together and putting all our kids together and kind of taking our turns, going over there and helping them out. We've discussed that. I don't know if we're still gonna do that because it seems like the older they get, the different disabilities, we all kinda group together instead of being – when they were younger, we could all be together. But we all have varying problems.”	Parent, Female
Live with Relative	
“I wouldn't – I don't think I would be ready for [Individual with IDD] living with me in my stage of life right now because I'm 27. But I know one day I would be very comfortable with that and very happy with that sort of when I'm older and have more of a settled lifestyle”	Sibling, Female
“Hopefully, she would be living on her own. If not, she would be living with maybe my daughter, and if she had a family, with them as well. So these are conversations that we have had and discussed all these things.”	Parent, Female
Independent Living	
“I would love for him to stay here and have someone come see him. That's why I bought the house. ... he really can live by himself, but he'd need someone to check up on him”	Parent, Female
“In the future when both my husband and I have died, [Individual with IDD] will be able to stay in his apartment. Because our home will go into his special needs trust, which is set up.”	Parent, Female

(Note: in some of the quotes, (I) indicates the Interviewer speaking, and (R) indicates the respondent (the parent or sibling) speaking. All names have been removed.)

3.3 | Housing

Planning for housing and living arrangements was the domain of future planning mentioned and discussed most often and in the most detail. 22 of the 25 (88%) parents and siblings interviewed discussed housing in some way. Some caregivers had already established detailed plans for future housing arrangements. Others had vague ideas about what the living arrangements would look like for their child. Almost all of the participants interviewed had at least thought about future living arrangements for their child. They identified this as one of the most important domains of planning.

TABLE 6 Legal planning

Power of attorney	Speaker
"Well, her older brother. He's got the power of attorney, so he would [...] wemet with the lawyer and wewent over everything. Then wetalked to [<i>the brother</i>] about it and told him where all the wills are and all that kind of information is.	Parent, Female
"Myself and my older brother, we would assume – we assume power of attorney over [Individual with IDD] and things like that. So we – so everything – every legal decision regarding [Individual with IDD] must be decided upon – between my brother and myself. And we will potentially take on full responsibilities that my parents have. Whether [Individual with IDD]'s residing with us or not, we'll be the – his guardians and – so to speak in the legal sense."	Sibling, Male
Legal guardianship	
"When I was 22 or 23, I became a legal guardian of my brother along with my parents...My brother was – I believe, he was 19 when my parents became – we all became his legal guardians – the three of us. He had to get his tonsils and adenoids out. [...] They wouldn't do the surgery unless my parents were his legal guardians. So that was what sparked it. [...] It was just assumed or just automatic that I would become a legal guardian."	Sibling, Female
Complexity and individuality of legal planning	
"Well, right now the way it works, there is an alternate guardian situation that if something happened to me, my sister and my son are down as co-guardians – co-alternate guardians. And the way it works is they have to go back to court and then become permanent guardians. So I would still expect that. My sister would have to handle the financial end of it. But the only expectation with this kind of guardianship is that you see the person four times a year. I know my sister would not do that. She would see her regularly. But my son's in New York, so I would guess he would see her when he could."	Parent, Female
"There's one that I've been really struggling with and that's the legal documentation that needs to be in place, the guardianship papers, et cetera. It seems that – so, they're fairly expensive to have put into place. That's why I haven't done that yet. And there's a gray area as to – in my mind – as to why these papers are needed and when this is actually a critical issue."	Parent, Female
"We made a conscious choice not to get guardianship for [Individual with IDD]. We worked his entire life to make him as competent as possible, and with the way people around him support him, he is able under their advice to make the proper decisions. [...] Just as a safeguard, the person who is becoming the employer of record is listed in [Individual with IDD]'s power of attorney as the person he would want to be his guardian if one had to be appointed"	Parent, Female

Some people planned or hoped for their child to move into a group home with staff and caregivers. Other families planned for a sibling or other relative to become the caregiver of their child and would have the child move in with that person in the future. Some parents planned for their child to live independently in their home or another home, with arrangements for staff or relatives to check in on them. Planning for housing ranged from very "aspirational" plans, where the families had hopes about their child moving in with relatives but no clear plan, to more "definitive" plans where clear discussions had taken place. However, very few families indicated that they had put housing plans in writing, or made anything official. For example, the mother from the following quote demonstrates that she has had discussions with her other children about her daughter with IDD living with them later in life, and yet, she also expresses an aspirational hope that her daughter with IDD might live on her own, but does not express having made any definitive plans for that housing scenario.

Hopefully, she would be living on her own. If not, she would be living with maybe my daughter, and if she had a family, with them as well. So these are conversations that we have had and discussed all these things.

Parent, Female

See Table 5 for subdomains and additional relevant interview quotes related to housing.

3.4 | Legal planning

The second domain of future planning involved legal considerations. This domain was the second most common domain discussed in interviews, with 15 (60%) of the parents and siblings mentioning legal planning. The primary forms of legal planning discussed by caregivers were assigning power of attorney and guardianship.

Some caregivers spoke with legal advisors to ensure the person who they wanted to take over legal power of attorney when they died, often one of their other children, could be properly designated. Another legal consideration discussed by caregivers was assigning a legal guardian for their child. This was often a sibling or another relative. In some families, the parents and another sibling could simultaneously be assigned legal guardianship, so that when the primary caregivers died, the sibling was already designated as a guardian. Even for caregivers who had put a lot of thought into legal guardianship, many still felt some degree of confusion or frustration in planning within this domain, demonstrated by the complexity of these parents' experiences. However, future planning can be very dependent on the needs of the person with IDD. In one case, the caregiver made a choice not to assign a legal guardian for their child, but still designated someone in the event that a guardian would be required to be appointed for their son in the future. In the quote below, one parent demonstrates the complexity of legal planning for her child with IDD and the barriers to planning in that domain, including expenses and a lack of understanding about what is most important.

There's one that I've been really struggling with and that's the legal documentation that needs to be in place, the guardianship papers, et cetera. It seems that – so, they're fairly expensive to have put into place. That's why I haven't done that yet. And there's a gray area as to – in my mind – as to why these papers are needed and when this is actually a critical issue.

Parent, Female

See Table 6 for subdomains and additional relevant interview quotes related to legal planning.

3.5 | Identification of a primary caregiver or overseer

The third domain of future planning, which was discussed by 14 (56%) of the parents and siblings interviewed, is the identification of a person or persons who will take over daily caregiving responsibilities and provide oversight for the adult with IDD. Some families had clearly decided and planned for who would become the primary caregiver in the future. Other families had given some thought to who might take over care and what that might look like, but had not explicitly had discussions or made arrangements for a future caregiver. Others had identified a network of people to share the caregiving responsibilities. While this action is a distinct domain in and of itself, the act of identifying a primary caregiver naturally overlaps with other domains of planning, as this is often the first step in planning within many other domains.

Many caregivers had identified one or more future primary caregiver(s). In some instances, but not all, this future primary caregiver was also the designated legal guardian. Others had ideas about who might take over caregiving responsibilities but had not made very clear arrangements for that to happen. For example, a few people indicated that they hoped their other, non-disabled children, would take over caregiving responsibilities, but they had not made many specific or concrete plans for this and sometimes had not discussed it explicitly with the other children. In some cases, a parent identified multiple people who would share the responsibilities of primary caregiver in the future, distributing different domains of care across different people. One especially skilled future planner created an entire “circle of support” for their child, to ensure that all needs would be met. This was created and designated through wills, a special needs trust, and the legal power of attorney process. In the exchange below, one parent indicates that she has identified a specific relative who will take on caregiving responsibilities for her child with IDD, yet also demonstrates that conversations about this plan have been more “cursory,” and she anticipates more definitive planning to occur in the future, now that a caregiver has been identified.

R: neither of us are getting any younger – so, the thinking is that one of [Individual with IDD]'s cousins will oversee the kids. Yeah.

I: And, oversee – by oversee, you mean what exactly?

R: Well, would be their guardians.

I: Okay. Okay. And, do you have a specific cousin picked out or –?

R: Yes.

I: And this is – have you guys had that conversation with this person?

R: On a cursory level. Not on a – not in detail. But, it is a conversation that will be coming within the next couple years, for sure [...] I shouldn't say – we've had the conversation. The details will be outlined – will be much more granular within the next couple years as we develop – as I get a better sense of the options that are available. (Parent, Female)

See Table 7 for subdomains and additional relevant interview quotes related to identification of a primary caregiver or overseer.

3.6 | Financial planning

The fourth domain the study team identified is financial planning. This domain was discussed almost as often as legal planning, with 11 (44%) of the parents and siblings who were interviewed mentioning financial planning. This primarily involved plans for a special needs trust, life insurance, a will or Medicaid disability waiver funding. The financial domain often overlapped with the legal domain.

Some caregivers had a plan for how finances would be provided to their child after they die, including setting up a special needs trust or designating funds in a will. Others had to consider how long-term funding, such as through a disability waiver program, may be affected by the location of relatives. In the quotation below, a parent discusses how her financial plans for her child are complicated by the location of relatives and waiver funding rules.

A lot of my future planning was based on selling my house here in Philadelphia and relocating to an area that was a little bit more reasonably priced and being free of my financial burden and it's not possible now, unless I want to forfeit [*the waiver funding*] for [Individual with IDD] ... That has a huge impact on long-term planning because long-term planning in terms of who would be caring with them and what their long-term future would look like, it would – I could see it being with family instead of in a group home, but I can't – the expectation of it being with family without having any kind of funding for any

TABLE 7 Identification of a primary caregiver or overseer

Caregivers identified primary caregiver	Speaker
[Speaking about a current staff caregiver]: "We have discussed this many times with her. And she said as long as she's willing and able and alive [laughs] she said she'll be very happy to help us."	Parent, Female
[Discussing the plan to have a local caregiver to move in and help with day-to-day and a non-local sibling to manage other things from afar]: "I: So it sounds like you have some type of plan for if you're not around or you're not able to take care of [Individual with IDD] for whatever reason – that you guys have kind of set this up that [local caregiver] can move in here and – R: And help. I: – help and then [sibling] could manage kind of the other stuff even from where she is currently. R: Right. I don't see them moving from Boston anytime soon. I really don't."	Parent, Female
Aspirational plans for primary caregiver	
"I: And what kind of people – I mean, who do you think will help support her as she continues to get older? Either when you're not there to do it, or just in general? R: I don't know. I'm not sure, hopefully my daughter."	Parent, Female
"I: Okay. And what kind of role do you think your son envisions for himself in [Individual with IDD]'s life and just in the future? R: I actually, honestly, haven't asked him that, but I will ask him that. That's a good question. Yeah, I'm gonna ask him. I just asked him to promise me that he'll take care of his brother. And he's very responsible. I know that he would. But I never asked him that question. I will." "R: neither of us are getting any younger – so, the thinking is that one of [Individual with IDD]'s cousins will oversee the kids. Yeah. I: And, oversee – by oversee, you mean what exactly? R: Well, would be their guardians. I: Okay. Okay. And, do you have a specific cousin picked out or –? R: Yes. I: And this is – have you guys had that conversation with this person? R: On a cursory level. Not on a – not in detail. But, it is a conversation that will be coming within the next couple years, for sure [...] I shouldn't say – we've had the conversation. The details will be outlined – will be much more granular within the next couple years as we develop – as I get a better sense of the options that are available."	Parent, Female
Network of caregivers	
"Well at this point, the friends are participating in a circle of support that we've set up. [...] one of my very close friends will become the employer of record [for his staff]. Another will become his rep and his power of attorney. And a third will be kind of boots on the ground – to do the weekly grocery shopping and order his medicine and kind of take care of important stuff, the more direct kinds of oversight. And it's all written out in our wills, in the special needs trust and in our various powers of attorney."	Parent, Female

TABLE 8 Financial planning

Plans for funding for child with IDD	Speaker
"We do have a trust set up and a will and all that stuff and my daughter would be the one that's gonna take care of him"	Parent, Female
"We've talked about the will and what would happen to the house and the funds and how everything is to be divided, with [Individual with IDD] getting the lion's share, but [Sibling] being the – obviously the conservator/trustee for her."	Parent, Female
"We also have a great attorney who made us take out this huge life insurance policy on me. So financially, I think it would be okay. I mean, I would suggest I think for other people to do financial planning. [...] There's a lot of lawyers out there that specialize in financial planning for people with disabilities. But you have to make sure you have a good person."	
Location of family and funding eligibility	
"The waiver funding is limited to the state of Pennsylvania. So, if I move out of Pennsylvania, we have to forfeit our waiver funding, which means there's – [...] there's family members who would be extremely supportive of [Individual with IDD] and his sister in Florida, only to find out after doing some recent research that if I leave the state of Pennsylvania, I forfeit that funding. [...] and that funding is really difficult to get in the state of Florida"	Parent, Female
"A lot of my future planning was based on selling my house here in Philadelphia and relocating to an area that was a little bit more reasonably priced and being free of my financial burden and it's not possible now, unless I want to forfeit [the waiver funding] for [Individual with IDD] ... That has a huge impact on long-term planning because long-term planning in terms of who would be caring with them and what their long-term future would look like, it would – I could see it being with family instead of in a group home, but I can't – the expectation of it being with family without having any kind of funding for any kind of activities or programs in place is just not – is – that's, in my opinion, an unrealistic request on family members."	Parent, Female
kind of activities or programs in place is just not – is – that's, in my opinion, an unrealistic request on family members.	Parent, Female

See Table 8 for subdomains and additional relevant interview quotes related to financial planning.

3.7 | Day-to-day care

The next domain of future planning involved thinking about the day-to-day care and activities of the adult with IDD. Planning in this domain included hiring and managing care staff, planning for chores and maintenance, and finding day programmes or job opportunities

TABLE 9 Day-to-day care

Day programmes and employment	Speaker
[Thinking about what will change 10 years out] "We've talked about oh, that one school upstate Pennsylvania. I can't think if what it's called right now. [...] It's a vocational school. [...] So I have toyed with that idea. So if he could get a vocation. I don't see him going to secondary school, even for a certificate program. I just think that would be a waste of time for him. He's not – academically, it's just not there for him and I think it would just torture him if I sent him through that."	Parent, Female
"He's now home because he's not been able to find a program that's appropriate and that takes the waiver that he's been assigned [...] He's in a power wheelchair, so he's limited for mobility or independent activities. He requires a one-on-one. He has a feeding tube, and he's not orally fed. It's continuous feed when we have it running. So with toileting and that kind of thing, he needs one-on-one assistance to transferring."	Parent, Female
"I would still like [Individual with IDD] to get a job. She's working on job training now. I think she's gonna get a job hopefully soon. But we're working on it."	Parent, Female
Management of staff	
"The person who most – is becoming the employer of record is actually 20 years younger than I am. The person who's becoming the rep payee is probably about 15 years younger than I am. The person who's doing the boots on the ground stuff is probably 30 years younger than I am. So we're set for a while [...] And the person who's doing the boots on the ground is willing to take over the medical power of attorney."	Parent, Female
Aspirational plans	
"I: what level of support do you think she would need if she was living on her own? R: Well, definitely in terms of money. She's very bad with money. She wouldn't know how to balance a checkbook or – I need to pay the gas bill or electric bill this month [...] and she can cook herself basic things, macaroni and cheese, chicken nuggets, whatever. But could she cook herself a whole big dinner? Probably not without someone helping her do that. [...] I don't think she'd ever be 100 percent on her own."	Parent, Female

for the adult with IDD. Only 6 (25%) of the parents interviewed discussed planning within this domain.

Some caregivers had identified a specific programme that their child could participate in while others described the barriers to finding a programme appropriate for the specific needs of their child. Another aspect of this domain was identifying a person or people who will be responsible for the management of staff. One caregiver described the various people she had identified to take care of the staff and the "boots on the ground" responsibilities. Another caregiver had identified the level of support that her child would need but did not appear to have made specific arrangements for this. In the following quote, a parent demonstrates some "aspirational" plans for the day-to-day care and activities of her

child with IDD in the future and considers what would be best based on his ability level; however, she has not decided on a definitive plan yet.

[Thinking about what will change 10 years out] We've talked about oh, that one school upstate Pennsylvania. I can't think if what it's called right now. [...] It's a vocational school. [...] So I have toyed with that idea. So if he could get a vocation. I don't see him going to secondary school, even for a certificate program. I just think that would be a waste of time for him. He's not – academically, it's just not there for him and I think it would just torture him if I sent him through that.

Parent, Female

See Table 9 for subdomains and additional relevant interview quotes related to day-to-day Care.

3.8 | Medical management

The next domain identified was medical management. Only 4 (16%) of the interviewees discussed their planning within this domain.

Some caregivers discussed how medical management is a complicated part of their child's care and acknowledged that they need to make more detailed plans in this area going forward. A few other caregivers mentioned the need to identify someone who would check on the person with IDD and ensure that they have their medications and are taking them properly. Surprisingly, the study team did not encounter much detailed planning surrounding medical care and needs. In the quote below, a parent explains how the medical care of her child with IDD has become more complicated in recent years, but indicates that she has not yet made a clear plan for how that medical management will continue in the future.

I spend a lot of time keeping on top of his medical care. In the last three, four years he's had a decline in his – just his focus and his awareness and – so it's taken a lot of coordination and – we discovered the adult Trisomy 21 Clinic, which we've been very thankful for. I was not aware of that at all before the last number of years because [Individual with IDD] had never been sick or never taken a pill, that kinda thing. [...] So right now it's me. My husband goes along. And we include staff on the phone or in decision-making, [...] I'm gonna retire in a month or two. So I will have some more time to think about it and look more long-term.

Parent, Female

See Table 10 for additional relevant interview quotes related to medical management.

3.9 | Transportation

A final domain was planning for transportation needs. This domain was discussed by 4 (16%) of the parents and siblings interviewed. For some families, this is an important issue to consider when the primary caregiver who transports their child to medical appointments, jobs, or day programmes, is no longer there. Some caregivers made plans to provide an accessible vehicle itself and manage the various logistics of arranging and paying for that, such as the parent in the following quote:

The other piece that we had to work out was who would own [Individual with IDD]'s wheelchair van. [...] You can't get insurance for a vehicle that you own if you don't drive... right now, we have the van as our third vehicle on our policy, and until the second of us dies, that is the way it can go. [Another caregiver] has a son who is very responsible and in fact is willing to take over for her when she can't handle [Individual with IDD] anymore. [...] her son agreed to be the owner – the registered owner of the vehicle and put it on his insurance. And the trust will pay for the vehicle.

Parent, Female

See Table 11 for subdomains and additional relevant interview quotes related to transportation.

4 | DISCUSSION

Despite many caregivers engaging in future planning to some extent, it is clear that there is a need for greater support and education for caregivers in creating plans for the future surrounding long-term care of an adult relative with IDD. Through this

TABLE 11 Transportation

Need for transportation assistance	Speaker
“I don't know that he's ever gonna be able to drive. I doubt it [...] But transportation for him to be able to go food shopping, get back and forth to work if he gets a job. That kind of stuff.”	Parent, Female
“So I'm sure when we get older and are not able to drive and all, yeah, it would be nice to have someone to call up and say, hey, can you drive her to here, drive her to here, that kind of thing, yes. [...] on Fridays she uses Transnet. All she has to do is call them up and say, pick me up, and she knows how to do that – to call them. [...] But for example, if she works at Chili's. Well, that's only a probably five minute drive from our house, but she has to be picked up and dropped off. And during the week, she needs to be in at 5:00. We both work until about 5:00, so that's when my other daughter picks her up and then we pick her up at 9:00.”	Parent, Female
Plans for accessible vehicle for adult with IDD	
“The other piece that we had to work out was who would own [Individual with IDD]'s wheelchair van. [...] You can't get insurance for a vehicle that you own if you don't drive... right now, we have the van as our third vehicle on our policy, and until the second of us dies, that is the way it can go. [Another caregiver] has a son who is very responsible and in fact is willing to take over for her when she can't handle [Individual with IDD] anymore. [...] her son agreed to be the owner – the registered owner of the vehicle and put it on his insurance. And the trust will pay for the vehicle.”	Parent, Female

TABLE 10 Medical management

Medical management	Speaker
“I spend a lot of time keeping on top of his medical care. In the last three, four years he's had a decline in his – just his focus and his awareness and – so it's taken a lot of coordination and – we discovered the adult Trisomy 21 Clinic, which we've been very thankful for. I was not aware of that at all before the last number of years because [Individual with IDD] had never been sick or never taken a pill, that kinda thing. [...] So right now it's me. My husband goes along. And we include staff on the phone or in decision-making, [...] I'm gonna retire in a month or two. So I will have some more time to think about it and look more long-term.”	Parent, Female
“I would like her to go into independent living, where still somebody will come in, like around the clock and just make sure she's taking the medication and going to the doctor and whatever.”	Parent, Female

qualitative study, the study team sought to examine the domains of care that need to be considered and planned-for by caregivers. Our findings confirmed previous research showing that the majority of caregivers do not make extensive or specific plans for the future (Freedman et al., 1997; Heller & Factor, 1991; Ryan et al., 2014). Even though most caregivers worry about what might happen to their child if they were no longer able to care for them, this does not always translate into extensive future planning. Further, previous research has shown that caregivers of adults with IDD already face many challenges including social and economic hardship and various physical and mental health issues, creating many barriers to undertaking the often complex process of long-term care planning (Black & McKendrick, 2010; McConkey, 2005; Taggart et al., 2012). There is a clear need for more support and education in this realm. Through in-depth interviews with siblings and parents of adults with IDD, the study team explored the nature of future planning for these individuals, including facilitators and barriers to creating long-term care plans. Through these interviews, the study team found that most discussions of future care and planning are vague and aspirational in nature, if plans exist at all. Nonetheless, the study team found that people are able to identify the domains of planning that they will need to think about as they make plans for the future and they can outline the framework of a plan that

should happen. Using a modified grounded theory approach and NVivo coding software, the study team identified a framework for the specific domains of future planning for long-term care that should be considered by caregivers in order to make definitive plans for the future of an adult relative with IDD. The domains identified were as follows: housing; legal planning; identification of primary caregiver(s); financial planning; day-to-day care; medical management; and transportation (See Tables 5–11). While previous research has looked at the barriers faced by caregivers and individual domains have been identified, the study team sought to create a more comprehensive framework of the domains of future planning for adults with IDD. The seven domains identified encompass many of the primary aspects of long-term care that caregivers must consider when planning for the future of their relative with IDD. Further, this analysis allowed for the identification of some key facilitators of planning that may allow caregivers to shift their planning from “aspirational” to more “definitive.”

Caregivers spoke about a wide range of planning activities and approaches to each domain, revealing subcategories within each. For example, in the domain of housing, some caregivers intended for their child with IDD to move in with a relative in the future, others planned for their child to live in group homes or alternative living arrangements paid for by the state, while others intended for their child to stay in their current home and have staff or family move in or check on them. This diversity of possibilities makes future planning a very complex activity requiring multiple decisions at each step of planning and within each domain of planning about what will be best for an individual. Additionally, within almost all domains the study team observed a spectrum of future planning abilities, ranging from caregivers who had made detailed, extensive plans, to those who had thought about the future vaguely but had taken very few concrete steps towards planning for their child or sibling's long-term care. For example, within the domain of legal planning, one parent had already assigned legal guardianship for their child with IDD to one of their other children, while other parents were still struggling to navigate the legal system and take the necessary steps to begin planning in this domain. While some caregivers had made detailed plans for the future, many families were often still confused about where to begin.

The domains outlined here are neither discrete nor mutually exclusive, but rather most of the domains overlap with one or multiple of the others. For example, when planning for housing, a caregiver must also necessarily set up a special needs trust to provide long-term funding for a home or alternative living arrangement. While creating a special needs trust, they may need to designate financial power of attorney, which in turn may lead them to designate a legal guardian and consult the legal process. Designating a legal guardian may then lead them to think about the issue of medical power of attorney and coordinating medical care, and so on. Thus, many of the domains intersect and “snowball” off of one another.

The study team noticed that much of this overlapping and snowballing can emerge from one initial domain: the act of identifying and having specific discussions with the person or persons who will

become the primary caregiver for the adult with IDD in the future. For many of the parents interviewed, the study team saw that if they had explicitly designated a person or group of people, whether that was one of their other children, a staff caregiver, or someone else in the community, and had begun to plan for how this person would ensure the proper care of the individual with IDD, it became clearer and easier to plan within many of the other domains. Thus, the authors suggest that the step of identifying and having a specific conversation with the person or people who will become the primary caregiver(s) responsible for care and oversight of the adult with IDD is a major facilitator of future planning. This aligns with previous findings from other researchers suggesting that families should identify a key person to oversee the well-being of their relative with IDD in order to better prepare for the future (Bigby, 2000; McConkey, 2005). Many parents are unsure of where to begin the large and daunting process of future planning for long-term care, and the simple step of identifying a future caregiver and having a discussion with them about what this role will involve and what the care will look like, may be the domain of future planning from which all the other domains emerge from.

Conversely, for those caregivers who had either not identified the primary future caregiver, or who only had vague ideas about who would take over, but had not had detailed conversations with that person yet, the other domains of planning remained vague and difficult to plan within. By identifying the primary caregiver or even in the case of one skilled planner, a “circle of support,” who will serve as the primary person or people responsible for making sure the adult with IDD is taken care of in the future, the other domains of planning can come into clearer focus and become easier to plan for. Naturally, the success of this step is highly dependent on having a person who is willing to take on the large responsibility of becoming the primary caregiver for an individual with IDD in the future and willing to help plan within many of these domains. Some current caregivers either may not have another child who could take on this role, or they feel that they do not want to “burden” their other children with this role in the future, leaving them uncertain about who will take over the care of their child with IDD when they are no longer able to do so. For caregivers in these situations, dividing the responsibilities of the current caregiver among multiple people may help them overcome the barrier of not having one obvious person who can take on the full role of primary caregiver. Creating a network of caregivers, with each person in the network only taking responsibility for one or some of the domains may ease the “burden” of this role and help facilitate future planning.

Many barriers to planning exist as well. Even for caregivers who do have someone who is willing and able to become the primary caregiver in the future, the systems and logistics of planning in other domains can still be very complex and confusing. For example, some people have decided who will take over legal guardianship, but still struggle with navigating the legal system, both logistically and financially, in order to accomplish this. Similarly, some people may have a relative identified who will take over care and even provide housing for the person with IDD, but if that person does not live in the same

area as the current caregiver, issues with waiver funding may arise, as this type of disability funding is often non-transferable across state lines. This qualitative study has demonstrated that there is a continuing need for better education and support within all of the domains of long-term care planning for adults with IDD.

Previous studies have shown that interventions that support caregivers in conducting future planning can be very successful in facilitating definitive long-term care planning. In one study, researchers evaluated an intervention for caregivers consisting of a legal/financial training session followed by small group training sessions. They found that this intervention significantly contributed to families completing a letter of intent, taking action on residential planning and developing a special needs trust. Further, they found that caregiver burden significantly decreased for families in the intervention group and daily choice-making of individuals with disabilities increased (Heller & Caldwell, 2006). Other reviews of research on this topic have shown that psychosocial interventions that aim to support ageing family caregivers and siblings of adults with IDD can be beneficial. Interventions included future planning, support groups, support services and sibling support interventions and interventions provided a range of services including education and training, counselling and advice on future planning, guardianship and financial planning (Ryan et al., 2014). This study reinforces the knowledge that families of adults with IDD often struggle to plan definitively for the future care of their relative, and the authors believe additional research and interventions such as those outlined above will continue to be beneficial in promoting better and more definitive future planning in families of adults with IDD. Our key findings that the domains of future planning tend to overlap and snowball off of one another and that identifying a primary future caregiver can facilitate better planning in other domains suggest that interventions should be structured to address many domains of planning together, with a particular emphasis on identifying and having open conversations about who will take over caregiver responsibilities when parents or siblings are no longer able.

One of the strengths of this study was the qualitative approach, which allowed us to gain in-depth insights and opinions from parents and siblings regarding their personal experiences with long-term care planning. The in-depth, one-on-one structure of these interviews may have allowed for researchers to establish greater trust and comfort with the subjects, such that they may have felt more comfortable sharing information that might not otherwise be discussed in a group setting or through a survey, which the authors believe is a potential strength of this approach as well. Additionally, interviewing both parents and siblings allowed the study team to understand multiple different perspectives on long-term care planning for a relative with IDD. Both of these perspectives are important for the development of improved policies, programmes and resources for adults with IDD. Further, the study team was able to interview many families of individuals with severe disabilities and lower functionality, allowing us to gain insight into the particular challenges faced by families of individuals with many complex needs.

One major limitation of our study was the recruitment mechanism through hospital clinics and advocacy groups, resulting in a convenience sample that was disproportionately knowledgeable about services and had been able to successfully access those services. Many families face extremely long wait lists to obtain waiver funding from the state, and this sample represented an unusual group of families that were able to obtain services like this without the long waits faced by most caregivers. Further, this sample was predominantly White and of higher socioeconomic status (SES). It will be important to replicate this study with diverse populations, in order to determine whether the findings from this sample of predominantly White, higher SES families are also true for other subgroups including African Americans, Hispanics, lower-income families and rural families, among others. However, even this more privileged group expressed that they faced many challenges related to long-term care planning and accessing services in a timely manner making it likely that these challenges are even greater for parents and siblings who are less connected to advocacy groups, have fewer resources or represent more disadvantaged groups. Further analysis is needed to determine whether the key findings from this study hold true for other subgroups, and the authors suggest additional research be conducted on this topic with diverse study populations. Additionally, the study team chose to interview both parents and siblings of adults with IDD, for the reasons described above. However, the study team did not choose to analyse the differences between these groups, and the mix of parents and siblings in our analysis of long-term care planning themes could compromise sample homogeneity.

5 | CONCLUSION

Based on the findings of this study, the authors suggest that further research be performed to evaluate the support and education needs of caregivers of adults with IDD in planning for the future. There is an emerging need for more robust future planning for long-term care of adults with IDD, and there is clearly a lack of support, resources and clarity for caregivers in trying to do so. The authors suggest that further studies look at the effectiveness of educational tools and support services for caregivers related to available resources. Interventions and support options that build on previously successful approaches (Heller & Caldwell, 2006; Ryan et al., 2014) could include creating a comprehensive guide for future planning that outlines all the essential domains, providing classes and support groups surrounding future planning and providing financial, legal and practical support services. Support approaches such as these could all potentially decrease confusion and increase planning abilities of caregivers such that they might be able to shift from "aspirational" to "definitive" planning (Taggart et al., 2012).

Further, due to our key finding, which aligns with previous researchers assertions (Bigby, 2000), that identification of a primary caregiver(s) may be the first essential step in future planning and can facilitate planning in many other domains, the authors suggest

research be conducted to more thoroughly examine differences in future planning among families who have taken this step and those who have not. Additional education about the importance of identifying a primary caregiver(s) and framing plans within other domains around that caregiver may also help increase confidence and success in future planning among current parents and caregivers.

ACKNOWLEDGEMENTS

This study was funded by a grant from the Oscar G. and Elsa S. Mayer Family Foundation.

CONFLICT OF INTEREST

Nothing to disclose.

ORCID

Jane Lindahl  <https://orcid.org/0000-0002-0765-6243>

REFERENCES

- Bigby, C. (2000). *Moving on without parents: Planning, transitions, and sources of support for middle-aged and older adults with intellectual disability*. Baltimore, MD: P.H. Brookes.
- Black, L. A., & McKendrick, V. (2010). *Careful plans report: A study of the aspirations of older carers of family members with a learning disability living in South Eastern Health and Social Care Trust (Older Families Service)*. Lisburn: Positive Futures. Retrieved from <https://www.positive-futures.net/cmsfiles/downloads/research/Careful-Plans-Report-May-2010.pdf>
- Bowey, L., & McGlaughlin, A. (2007). Older carers of adults with a learning disability confront the future: Issues and preferences in planning. *The British Journal of Social Work*, 37(1), 39–54. <https://doi.org/10.1093/bjsw/bcl052>
- 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: JARID*, 31(2), 226–235. <https://doi.org/10.1111/jar.12379>
- Bruininks, R., Woodcock, R., Weatherman, R., & Hill, B. (1996). *Scales of independent behavior – Revised (SIB-R)*. Meadows, IL: Riverside.
- Davys, D., & Haigh, C. (2007). Older parents of people who have a learning disability: Perceptions of future accommodation needs. *British Journal of Learning Disabilities*, 36(1), 66–72. <https://doi.org/10.1111/j.1468-3156.2007.00447.x>
- Davys, D., Mitchell, D., & Haigh, C. (2010). Futures planning, parental expectations and sibling concern for people who have a learning disability. *Journal of Intellectual Disabilities*, 14(3), 167–183. <https://doi.org/10.1177/1744629510385625>
- Freedman, R. I., Krauss, M. W., & Seltzer, M. M. (1997). Aging parents' residential plans for adult children with mental retardation. *Mental Retardation*, 35(2), 114–123. [https://doi.org/10.1352/0047-6765\(1997\)035<0114:APRPPFA>2.0.CO;2](https://doi.org/10.1352/0047-6765(1997)035<0114:APRPPFA>2.0.CO;2)
- Glaser, B. G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press. Retrieved from <https://trove.nla.gov.au/version/10177421>
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New Brunswick, NJ: Routledge.
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research Electronic Data Capture (REDCap) – A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, 42(2), 377–381. <https://doi.org/10.1016/j.jbi.2008.08.010>
- Hays, R. D., Bjorner, J. B., Revicki, D. A., Spritzer, K. L., & Cella, D. (2009). Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items., Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. *Quality of Life Research*, 18(7), 873–880. <https://doi.org/10.1007/s11136-009-9496-9>
- Heller, T., & Caldwell, J. (2006). Supporting aging caregivers and adults with developmental disabilities in future planning. *Mental Retardation*, 44(3), 189–202. [https://doi.org/10.1352/0047-6765\(2006\)44\[189:SACAAW\]2.0.CO;2](https://doi.org/10.1352/0047-6765(2006)44[189:SACAAW]2.0.CO;2)
- Heller, T., & Factor, A. (1991). Permanency planning for adults with mental retardation living with family caregivers. *American Journal of Mental Retardation*, 96(2), 163–176.
- Maenner, M. J., Smith, L. E., Hong, J., Makuch, R., Greenberg, J. S., & Mailick, M. R. (2013). Evaluation of an activities of daily living scale for adolescents and adults with developmental disabilities. *Disability and Health Journal*, 6(1), 8–17. <https://doi.org/10.1016/j.dhjo.2012.08.005>
- McConkey, R. (2005). Fair shares? Supporting families caring for adult persons with intellectual disabilities. *Journal of Intellectual Disability Research: JIDR*, 49(Pt 8), 600–612. <https://doi.org/10.1111/j.1365-2788.2005.00697.x>
- NVivo Qualitative Data Analysis Software (2015). QSR International Pty Ltd. Version 11.
- 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>
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques* (2nd ed.). Newbury Park, CA: SAGE Publications Inc.
- 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>
- Weeks, L. E., Nilsson, T., Bryanton, O., & Kozma, A. (2009). Current and future concerns of older parents of sons and daughters with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 6(3), 180–188. <https://doi.org/10.1111/j.1741-1130.2009.00222.x>
- Zarit, S. H., Orr, N. K., & Zarit, J. M. (1985). *Families under stress: Caring for the patient with Alzheimer's disease and related disorders*. New York, NY: New York University Press.

How to cite this article: Lindahl J, Stollon N, Wu K, et al.

Domains of planning for future long-term care of adults with intellectual and developmental disabilities: Parent and sibling perspectives. *J Appl Res Intellect Disabil*. 2019;32:1103–1115.

<https://doi.org/10.1111/jar.12600>