


# Future Planning Among Families of Individuals With Intellectual and Developmental Disabilities: A Systematic Review

Chung eun Lee  and Meghan M. Burke

University of Illinois at Urbana—Champaign College of Education, Champaign, IL, USA

## Abstract

Considering individuals with intellectual and developmental disabilities (IDD) are having longer lives and outliving their parents, future planning has emerged as one of the most important topics in the IDD field. Without future planning, individuals with IDD and their families may be at greater risk for negative outcomes such as inappropriate living conditions of individuals with IDD (e.g., institutions) and greater anxiety for families. Thus, it is important to examine future planning for individuals with IDD. The purpose of this review was to synthesize the literature about future planning among families of individuals with IDD. Specifically, the purpose was to summarize the literature with respect to: existing future plans, barriers to future planning, benefits of future planning, and correlates of future planning. A systematic literature review was conducted about future planning among families of individuals with IDD. In total, 43 studies were identified. Results indicated that few families have conducted future planning for individuals with IDD. Further, family caregivers (e.g., siblings and parents) reported different barriers. However, conducting future planning benefitted all family members including individuals with IDD. It is necessary to conduct future planning with all family members, including individuals with IDD. Further, it is critical to include individuals with IDD in research about planning. Implications for future research, policy, and practice are discussed.

**Keywords:** family caregiver, future planning, intellectual and developmental disabilities, systematic literature review

## Introduction

Considering individuals with intellectual and developmental disabilities (IDD) are having longer lives and outliving their parents, future planning for individuals with IDD has emerged as one of the most important topics in the IDD field (Hodapp, Sanderson, Meskis, & Casale, 2017). Without future planning, individuals with IDD and their families are at greater risk for negative outcomes such as inappropriate living conditions of individuals with IDD (e.g., institutions, Hewitt, Agosta, Heller, Williams, & Reinke, 2013) and greater anxiety for families, including parents and siblings (Smith, Tobin, & Fullmer, 1996).

Yet, few families conduct future planning. In a recent national survey (i.e., The Family and Individual Needs for Disability Supports or FINDS), almost 54% of family caregivers reported that they did not develop future plans for their family members with IDD (Anderson et al., 2018). The lack of future planning occurred in spite of serious concerns about the future (e.g., an absence of quality supports and services, lack of self-advocacy skills of individuals with IDD, declining health of individuals with IDD). The

purpose of this study was to synthesize the extant literature about future planning. Specifically, to examine the current state of future planning as well as barriers, benefits, and correlates of future planning.

Half of families have not conducted future planning (Anderson et al., 2018); of the families who have conducted future planning, their plans often are not comprehensive. Burke, Arnold, and Owen (2018) conducted a national study about the prevalence of future planning. The most common future planning activities were aspirational activities (e.g., having an informal conversation with family members about the future). Definitive future planning activities (e.g., developing a special needs trust; developing a residential plan) were infrequently conducted among families. Unfortunately, this study was limited to the perspectives of parents of individuals with IDD; it did not include the perspectives of siblings or individuals with IDD. Also, this study was limited to the United States.

In a systematic review of the literature about future planning, Bibby (2013) reviewed 16 articles to identify barriers to future planning among families of individuals with ID. Barriers included: lack of quality care in the adult service delivery system, difficult relationships with professionals, interdependency between parents and siblings, lack of information about alternatives to family care, difficulty in discussing planning given its

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Correspondence: Chung eun Lee, Special Education, University of Illinois at Urbana—Champaign College of Education, 1310 S. 6th St, 288 Education building, Champaign, IL 61820-6925, USA. E-mail: celee1212@gmail.com

emotional nature, caregiver reluctance to let go of their caregiver role, caregiver sense of duty, individual with ID fears independent living, caregiver concern regarding loss of control, and individual with ID unwilling to leave the family home. Among those barriers, only three barriers (i.e., lack of quality care, difficult relationships, and interdependency between parents and siblings) were consistent across the 16 articles. The other barriers may not be generalizable given their low frequency. Further, this review was limited to studies conducted in the United Kingdom. Given the different service delivery systems across countries, barriers may differ.

In addition to barriers, it is important to examine the benefits of future planning. Given that families experience greater stress without long-term planning, conducting future planning may have several benefits. For example, DaWalt, Greenberg, and Mailick (2018) tested a future planning intervention with parents and their offspring with autism spectrum disorder (ASD). They found that the intervention was effective with respect to: reducing parent depressive symptoms and increasing definitive planning activities. However, their study was underpowered to detect significant effects given the small sample size reported by researchers; also, their study was limited to adolescents with “high functioning” ASD and their parents.

Despite the benefits of future planning, few researchers have examined the correlates of future planning. By identifying the correlates, we can determine who is most likely to conduct planning and who is most likely to need interventions or support to facilitate future planning. Freedman, Krauss, and Seltzer (1997) found that when parents were older, had poorer health, were single, and had offspring with mild or moderate disabilities, they were more likely to conduct residential planning. It is important to determine whether these findings were replicated by other studies to identify risk factors or facilitators to future planning.

Given the increased longevity of individuals with IDD, it becomes increasingly important to understand the experiences of families in long-term planning. As a first step, it is important to summarize the extant international research about future planning. Thus, the purpose of this study was to extend the literature by conducting a systematic review of future planning. Specifically, the following research questions (RQs) guided this literature review: (RQ1) What are the existing future plans of families of individuals with IDD?, (RQ2) What are the barriers to future planning?, (RQ3) What kind of interventions and instruments are available to facilitate future planning?, (RQ4) What are the benefits of conducting future planning?, and (RQ5) What are the correlates of future planning?

## Method

### Eligibility Criteria

The inclusionary criteria required that articles: were published in a peer-reviewed journal, included empirical data, included families of individuals with IDD, reflected future planning for individuals with IDD, and were published in English. Notably, “family” was defined broadly to include nuclear (e.g., parents) and extended family members (e.g., grandparents). Given the importance of involving family members in future planning, it is

appropriate to include different types of caregivers in the included studies. No other inclusionary criteria (e.g., years of publication, the quality of the study) were included to ensure a broad collection of articles were reviewed.

### Literature Search

Articles were identified in two phases. First, an online literature search was conducted through using the following databases: ERIC, PsychINFO, and Academic Search Complete. Multiple combinations of keywords and descriptions were used to define the participants (i.e., *caregivers, family, sibling, parent*), the type of disability (i.e., *autism, Down syndrome, intellectual disability, developmental disability, learning disability, mental retardation*), and research topic (i.e., *future planning, transition planning, permanency planning*). During the second phase, a hand search of reference lists from included studies and relevant book chapters was conducted. We further identified studies through an iterative process called pearl growing (i.e., using known eligible studies to improve search terms). For example, we used future planning intervention studies (DaWalt et al., 2018; Heller & Caldwell, 2006) to review their cited references. After identifying eligible studies, we searched the reference lists and conducted a forward citation search. Additionally, we hand-searched specific journals (e.g., *Journal of Policy and Practices in Intellectual Disabilities*) to find any eligible studies that were not identified in the database search.

The initial search yielded 706 studies. We first screened the titles for relevance to our RQs. Correspondingly, 182 articles were selected for an abstract review. After exporting the titles and abstracts into Microsoft Excel, the first author reviewed the studies based on our questions. Then, we selected 50 studies for a full review. We retrieved and reviewed the full-text of studies for which we needed additional information to determine eligibility. If studies were excluded during the full-text review, we recorded the specific reason for doing so. We (i.e., two independent reviewers) concurrently reviewed the 50 articles separately and then discussed any discrepancies until consensus was reached. The final number of studies meeting the criteria was 43 (see Figure 1).

### Coding Procedures

With 43 included studies, the authors coded the studies with respect to the: participants (e.g., sample size), research design (e.g., qualitative, quantitative, or mixed methods), and findings (see Table 1). All included studies were independently coded by both authors. To assess inter-rater reliability, the authors calculated the extent of agreement between the coders with respect to each code (e.g., sample size, method) by taking the total number of exact agreements, divided by agreements plus disagreements, multiplied by 100%. Overall, there was 95.65% agreement between the coders. Specifically, with respect to the findings, both authors independently and distinctly coded the findings for each of the RQs. Agreement was high for each question (RQ1 = 95.2%, RQ2 = 97.3%, RQ3 = 100%, RQ4 = 97.82%, and RQ5 = 92.3%). For the codes that had disagreements, the authors discussed the codes until a consensus was reached.

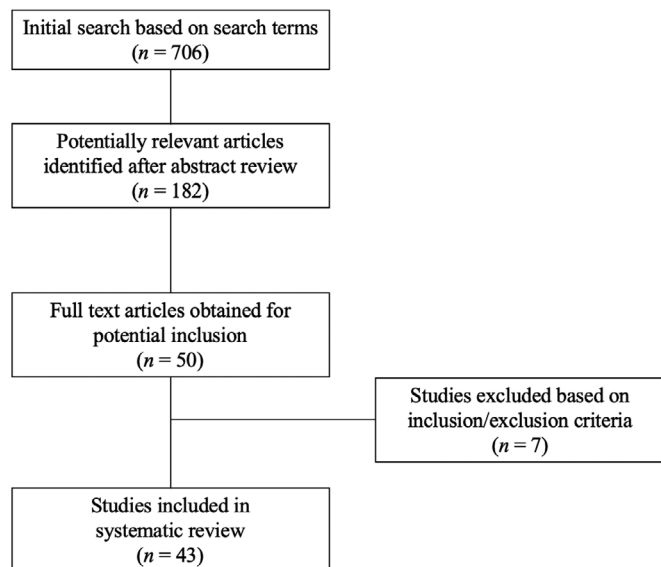


FIGURE 1

Flow of studies through the selection process.

## Results

### Participants

A total of 3221 family members of individuals with IDD were included in the 43 studies. Participants ranged from 18 to 98 years old. All studies included family members of individuals with IDD (e.g., parents, family caregivers). Overall, 21 studies (48.84%) included family members but did not specify the type of family role (e.g., parents or siblings). Of the 43 studies, 27.91% ( $n = 12$ ) only reflected the perspectives of parents while nine studies (20.93%) only focused on the perspectives of siblings of individuals with IDD. In addition, four studies (9.30%) included individuals with IDD and three studies (6.98%) included professionals. Notably, the collective percentages exceeded 100% due to overlapping participant groups. For example, a few studies included both parents and professionals. The majority of respondents were female. Specifically, 21 studies had samples wherein at least 80% of the participants were female. Also, only 21 studies reported the ethnicity of the participants; of those studies, most respondents were White (87.20%,  $n = 1485$ ). Further, 60.47% ( $n = 26$ ) of the studies were conducted in a variety of locations (e.g., Australia, Canada, Ireland, and UK); the remainder was conducted in the United States.

### Methods

Different research methods were used in the 43 studies. Ten studies used quantitative methods. Among these 10 studies, three studies used randomized controlled trials to test future planning interventions (Botsford & Rule, 2004; DaWalt et al., 2018;

Heller & Caldwell, 2006). Qualitative methods were used in 25 studies. While most studies did not specify their framework or paradigm, five studies employed the phenomenological method (Davys, Mitchell, & Haigh, 2015; Gauthier-Boudreault, Couture, & Gallagher, 2017; Holl & Morano, 2014; Knox & Bigby, 2007; Walker & Hutchinson, 2018) and two studies conducted action research (Craig & Cartwright, 2015; Young et al., 2018). Most ( $n = 18$ ) studies included individual interviews. The other studies included focus groups and open-ended questions from a survey. Eight studies used mixed methods; two of which were intervention studies (Bigby, Ozanne, & Gordon, 2002; DaWalt et al., 2018).

### Findings

The summary of results is organized into the following five sections: (a) existing plans for the future ( $n = 15$  studies); (b) barriers to future planning ( $n = 31$  studies); (c) interventions and instruments to facilitate future planning ( $n = 7$  studies); (d) benefits of future planning ( $n = 3$  studies); and (e) correlates of future planning ( $n = 5$  studies).

### RQ1: Existing Future Plans

Few families made plans for the future. Most parents anticipated to continue to care for their offspring with a disability (McConkey et al., 2006). As such, Prosser (1997) reported that only 28% of the participants had made future plans for their family members with IDD. Even more dismal, in a study by Bigby (1996), only 15% of the participants made future plans. Similarly, individuals with IDD reported that they had either not started planning for their futures or had only started some informal discussions within their families (Morningstar et al., 1995).

In regard to families who had conducted future planning, the extent and type of future planning varied. Interestingly, most future plans reflected aspirational (vs. definitive) planning activities (Bigby, 1996; Bowey & McLaughlin, 2007; Brennan, Murphy, McCallion, & McCarron, 2018; Burke et al., 2018; Davys et al., 2015; Walker & Hutchinson, 2018). For example, in a national sample of 388 parents of individuals with IDD, the most common future planning activities included: (a) locating an attorney knowledgeable about disability issues and (b) discussing future plans with the entire family (Burke et al., 2018). Few families engaged in definitive future planning activities (e.g., writing a letter of intent). Indeed, future planning is often done informally (Bigby, 1996). Further, families have reported being unsure whether their aspirational plans can be implemented as the plans lacked clarity and detail (Davys et al., 2015).

### RQ2: Barriers to Future Planning

Across 31 studies, barriers to future planning included: emotional demands, inertia, lack of information, lack of communication among family members, support needs of individuals with IDD, conflicts between individuals with IDD and their family members, siblings balancing their own lives, and systemic barriers.

TABLE 1  
Summary of article review

Author(s)/year	Purpose of the study	Participants	Location	Method	Main findings
Arnold et al. (2012)	To identify the needs of siblings of individuals with DD	139 siblings	USA	Survey	RQ2: Siblings who plan to provide care for individuals with IDD reported needing future planning and a formal support system
Baumbusch et al. (2017)	To examine caregiving dynamics in families of adults with ID	8 family members	Canada	Qualitative	RQ1, 2: Family members avoided future planning or did little planning. Family members perceived that siblings would be caregivers in the future
Bigby (1996)	To examine the nature and effectiveness of future planning	62 adults with ID and their relatives	Australia	Qualitative	RQ1: Parents made four future plans: implicit key person succession plans, explicit key person succession plans, financial plans, and residential plans. Only 15% of the families had comprehensive plans
Bigby et al. (2002)	To evaluate case management programs	44 family caregivers	Australia	Mixed methods	RQ3: After completing the programs, caregivers reported increased access to services and knowledge and reduced parental stress
Botsford and Rule (2004)	To evaluate a psychoeducational intervention with 27 mothers	27 mothers	USA	Quantitative	RQ3: The mothers in psychoeducational group demonstrated increases in knowledge and awareness of resources for planning
Bowey and McGlaughlin (2007)	To examine the views of older caregivers about future planning	62 family caregivers	UK	Qualitative	RQ1, 2: Almost 55% of caregivers reported that they were not ready or were unwilling to make plans. Barriers included: lack of awareness, emotional difficulties, and lack of confidence
Brennan et al. (2018)	To elicit the nature of future planning	17 family caregivers	Ireland	Qualitative	RQ1, 2: Most family caregivers reported that no definitive plans had been made. As a result, siblings reported creating plans during crises
Burke et al. (2018)	To examine the correlates and barriers to future planning	388 parents	USA	Quantitative	RQ1, 2, 5: Positive correlates with planning were: parent age and education and children with fewer abilities. Barriers included: lack of services, finances, reluctance, lack of time, emotional difficulty, and inertia
Burke, Fish, and Lawton (2015)	To examine current and future caregiving siblings	42 siblings	USA	Qualitative	RQ2: Anticipated sibling caregivers were concerned about future planning and transitioning to caregiver roles due to the uncertainty of the future

(Continues)

TABLE 1  
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Author(s)/year	Purpose of the study	Participants	Location	Method	Main findings
Campbell and Essex (1994)	To identify barriers and facilitators to future planning	32 parents	USA	Mixed methods	RQ2: Only 28% of parents discussed future plans. Parents reported barriers including: lack of information, costs, lack of understanding by professionals, and difficulty in accessing services
Chambers et al. (2004)	To explore perceptions of transitions to adult life	16 family members	USA	Quantitative	RQ1, 2: Both parents and siblings reported limited information in regard to post-school options for individuals with ID
Covelli et al. (2018)	To explore how caregivers see the future	28 family caregivers and professionals	Italy	Qualitative	RQ2: Health professionals perceived that parents were not ready to discuss the future due to fear
Coyle et al. (2014)	To examine the transition of caregiving roles	15 siblings	USA	Qualitative	RQ4: Although siblings expected to be caregivers, there were no concrete plans. Siblings who were involved in future planning were less stressed and more prepared for the transition of caregiver roles
Craig and Cartwright (2015)	To explore future planning among multiple people	49 individuals with ID, parents, and professionals	Australia	Qualitative	RQ1, 3: Caregivers reported support needs such as: respite and family support. As every family was different, future planning varied. The quality living 10-year plan can help people with disabilities and their families to develop plans with steps and strategies
Davy's et al. (2015)	To identify barriers to future planning	15 siblings	UK	Qualitative	RQ1, 2: Future plans varied across families; however, plans lacked detail. Barriers to planning included: anxiety, difficulty with services, superstition, expectations for siblings, balancing siblings' lives, health concerns, and funding
DaWalt et al., (2018)	To evaluate a multi-family group psychoeducation intervention	41 individuals with ASD and their parents	USA	Mixed methods	RQ3: Parents reported increased problem-solving skills, decreased depressive symptoms, and increased happiness
Dillenburger and McKerr (2011)	To explore issues related to caring and future planning	29 family caregivers	UK	Qualitative	RQ1, 2: Majority of caregivers had not made future plans and had not discussed planning with their offspring with IDD. However, most caregivers acknowledged the importance of future planning

(Continues)

TABLE 1  
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Author(s)/year	Purpose of the study	Participants	Location	Method	Main findings
Freedman et al. (1997)	To assess families' residential plans and placement preferences	340 mothers	USA	Quantitative	RQ1, 2, 4, 5: Mothers who made plans were more likely to have positive well-being, less future concerns, and greater sense of purpose in life
Gauthier-Boudreault et al. 2017	To explore the transitions of young adults with ID	14 parents	Canada	Qualitative	RQ2: Parents reported that their needs were not met during the transition process. Their needs included: information and material support
Gilbert et al., 2008	To explore perceptions of future housing needs	28 family caregivers	UK	Qualitative	RQ2: Although many family caregivers perceived residential care as the only option, they had negative views about residential care
Griffiths and Unger (1994)	To examine perceptions of caregiving and future planning	41 parent-sibling dyads	USA	Quantitative	RQ2, 4, 5: Family communication about future planning increased the likelihood of future sibling caregiving and decision making
Heller and Caldwell (2006)	To determine the effectiveness of a future planning intervention	48 family members	USA	Quantitative	RQ3: Families who participated in the intervention "Future is Now" reported completing a letter of intent, taking action on residential planning, and developing a special needs trust
Heller and Factor (1993)	To identify the correlates of financial/residential planning	100 parents	USA	Quantitative	RQ5: Caregivers who had greater family incomes, were older, and were White, were more likely to conduct financial and residential planning
Heller and Kramer (2009)	To identify facilitators to sibling involvement in future planning	139 siblings	USA	Quantitative	RQ1, 5: Few families made plans or involved siblings in future planning
Herrema et al. (2017)	To assess the nature and scale of concerns regarding the future	120 family members	UK	Mixed methods	RQ1, 2: Families of adults with ASD may experience frequent concerns about the future. Indeed, 64% of them were unprepared for the future
Hole, Stainton, and Wilson (2013)	To explore the perspectives toward the future	22 adults with ID and their family members	Canada	Qualitative	RQ2: Future concerns included: concerns for their aging parents, future living arrangements, and loneliness. Many of the family members recognized the importance of proactive planning
Holl and Morano (2014)	To understand the needs of adult siblings	15 siblings	USA	Qualitative	RQ2: Almost all siblings reported the need for more information about services and future planning. Parents refused to discuss future planning which resulted in frustration among siblings

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TABLE 1  
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Author(s)/year	Purpose of the study	Participants	Location	Method	Main findings
Knox and Bigby (2007)	To explore the perceptions of family care arrangements	16 family members	Australia	Qualitative	RQ2: Several siblings reported that the timing for discussion of future plans was delayed until their parent was ready
Leonard et al. (2016)	To describe engagement in transition planning	340 parents	Australia	Mixed methods	RQ1, 2: Although the majority of parents were involved in transition planning, only half of the individuals with ID were involved in transition plans
McConkey, Mulvany, and Barron (2006)	To identify the caregiver's preferences for housing and support options	387 family caregivers	Ireland	Mixed methods	RQ1: Most family caregivers anticipated individuals with ID continuing to live with family members. Few caregivers made future plans
Morningstar, Turnbull, and Turnbull (1995)	To examine the perspectives in regard to family influence on future and transition planning	40 individuals with IDD	USA	Qualitative	RQ1, 2: Individuals with IDD reported that their families have helped them to develop a future vision related to career and lifestyle options
Petriwskyj, Adkins, and Franz (2017)	To explore future planning	21 parents and professionals	Australia	Qualitative	RQ1, 2: Parents reported a few factors that may have an impact on planning: cost, care, lifestyle, employment, and continuing education
Prosser (1997)	To determine factors affecting future planning	32 family caregivers	UK	Qualitative	RQ1, 2: Only 28% of caregivers had made residential plans. Also, 63% of the caregivers had made some arrangement for financial security
Raghavan, Pawson, and Small (2013)	To explore transitions from school to adult life	43 family members	UK	Qualitative	RQ2: Although transition planning occurred in school, it was relatively later in the student's school life and lacked detail
Rawson (2010)	To explore perceptions of future planning and needed supports	13 siblings	UK	Qualitative	RQ2: Although many siblings anticipated caregiving responsibilities, they reported being unprepared
Reilly and Conliffe (2002)	To examine how families develop a planning instrument	31 family caregivers	Ireland	Qualitative	RQ1, 3: The authors developed an 11-page instrument "What the Future Holds." By using this instrument, families could discuss future planning
Rossetti and Hall (2015)	To examine sibling relationships	79 siblings	USA	Qualitative	RQ2: Siblings were unprepared with the transition to caregiving. Siblings reported needing information about future planning and caregiving

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TABLE 1  
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Author(s)/year	Purpose of the study	Participants	Location	Method	Main findings
Smith et al. (1996)	To use a peer support model to facilitate planning	30 parents	USA	Quantitative	RQ3, 5: From participating in a peer support model program, families reported increased knowledge and more opportunities to interact with parents
Taggart, Truesdale-Kennedy, Ryan, and McConkey (2012)	To examine caregiving demands and perceptions of planning	112 family caregivers	Ireland	Mixed methods	RQ2: Families felt uncomfortable talking about future planning. Almost half of the family caregivers made definitive future plans while the rest made aspirational plans
Tozer and Atkin (2015)	To explore sibling relationships, advocacy, and future planning	21 siblings	UK	Qualitative	RQ2: Siblings felt excluded from discussions about disability services. Siblings were frustrated by the lack of future planning and difficulty in initiating conversations with parents
Walker and Hutchinson (2018)	To explore caregiving and determining future plans	17 parents	Australia	Qualitative	RQ1: Overall, parents were aware of the need to conduct future planning; however, most parents had not made any plans. Of the family who made plans, most were aspirational plans
Weeks, Nilsson, Bryanton, and Kozma (2009)	To explore preference for housing and care options	132 family members	Canada	Mixed methods	RQ2: Families reported key issues: worry about future care, concern about services, and limited housing and care options
Young et al. (2018)	To describe the actions in the transition to adulthood	26 family caregivers	Canada	Qualitative	RQ2: Caregivers reported that they received resources for transition planning

ASD, autism spectrum disorder; DD, developmental disability; DS, Down syndrome; ID, intellectual disability; IDD, intellectual and developmental disabilities; RQ1, existing future plans; RQ2, barriers to future planning; RQ3, interventions and instruments to facilitate future planning; RQ4, benefits of conducting future planning; RQ5, correlates of future planning.

**Emotional demands.** Eighteen studies found that the emotionally demanding nature of planning prevented many families from conducting future planning. Due to the uncertainty of the future for individuals with IDD, both parents and siblings of individuals with IDD reported: stress, caregiving burden, and loneliness. For example, a mother of an adult with IDD reported:

Well from the day he was born until the day I die, I have that worry on my head when I put my head on the pillow until I rise in the morning. If I die, what is going to happen to [my son] or will anybody be good to him? (Taggart et al., 2012, p. 226)

Indeed, previous studies indicated that parents refused to engage in future planning due to fear about their own mortality and

difficulties in letting go of their caregiving roles (Bowey & McGlaughlin, 2007; Covelli, Raggi, Paganelli, & Leonardi, 2018; Herrema et al., 2017; Holl & Morano, 2014; Prosser, 1997). They also reported guilt about leaving their caregiving roles to their offspring without disabilities (i.e., the siblings of individuals with IDD, Griffiths & Unger, 1994). Because of these emotionally demanding issues, parents reported avoiding future planning (Hole et al., 2013).

Siblings were also concerned about the emotional demands of future planning. Siblings reported worrying about overcoming the challenges related to future planning (Burke et al., 2015). Siblings felt anxious and stressed about fulfilling caregiving roles for their brothers and sisters with IDD; specifically, siblings were apprehensive about whether they would be high-quality caregivers like their parents (Covelli et al., 2018; Davys et al., 2015).



**Inertia.** A few parents and siblings reported “inertia” as a barrier to future planning. For parents of adults with IDD, it was easier not to think about the future. Likewise, a few siblings had not thought about their future roles for their brothers and sisters with IDD. Siblings reacted to situations as issues arose instead of making plans; thus, siblings were more “reactive” than “proactive” when thinking about the future (Davys et al., 2015). Individuals with IDD also reported that they were too young to worry about future planning (Morningstar et al., 1995).

**Lack of information.** Six studies identified lack of information about future planning as a barrier. Specifically, parents reported that they were not engaged in future planning due to a lack of information. Such information included: financial information (e.g., how to create a special needs trust, Campbell & Essex, 1994; Rawson, 2010), legal information (e.g., whether to pursue guardianship, Rawson, 2010), and post-school options for individuals with IDD (e.g., how to secure employment, Chambers, Hughes, & Carter, 2004; Gauthier-Boudreault et al., 2017; Raghavan et al., 2013). Non-English speaking families may encounter greater difficulties in accessing information due to language barriers (Raghavan et al., 2013). For example, South Asian caregivers had difficulties accessing disability benefits and conducting planning due to lengthy claim forms and difficult terminology.

Notably, parents and siblings reported receiving little information about future planning. Specifically, parents received limited information during transition planning in high school (Gauthier-Boudreault et al., 2017; Raghavan et al., 2013). For example, although there were four or five professionals in the transition planning meeting, the professionals did not provide families with enough information to navigate the last years of school (Gauthier-Boudreault et al., 2017). Siblings also reported a lack of legal and financial information. For example, siblings reported feeling unprepared due to a lack of knowledge about: guardianship, power of attorney, special needs trusts, and formal benefits (Rawson, 2010). Usually, parents managed the legal and financial matters; thus, most siblings were not involved in these processes. Further, parents may not inform siblings about guardianship or the disability benefit system (Rawson, 2010). Therefore, siblings were unaware of legal and financial information; as a result, siblings reported feeling unable to conduct future planning.

**Lack of communication among family members.** Eleven studies identified the lack of communication among family members as a barrier to future planning. Most families assumed that caregiving responsibilities would fall to the siblings of individuals with IDD (Hodapp et al., 2017). However, parents often did not discuss planning with siblings (Coyle, Kramer, & Mutchler, 2014). The reluctance of parents to include siblings may relate to their fear of “burdening” the offspring without disabilities (Griffiths & Unger, 1994). Thus, parents (vs. siblings) were often the primary decision makers for future planning (Arnold, Heller, & Kramer, 2012; Chambers et al., 2004; Heller & Kramer, 2009; Rawson, 2010; Tozer & Atkin, 2015).

In addition, the literature also indicated that parents did not discuss future planning with their offspring with IDD (Chambers et al., 2004; Dillenburger & McKerr, 2011; Knox & Bigby, 2007; Leonard et al., 2016; Morningstar et al., 1995). Indeed, studies which included

parent perspectives (Chambers et al., 2004; Dillenburger & McKerr, 2011; Knox & Bigby, 2007) and the perspectives of individuals with IDD (Morningstar et al., 1995) found that individuals with IDD were not included in future planning. Notably, in some circumstances, individuals with IDD or siblings may not want to engage in future planning (Burke et al., 2018).

**Support needs of individuals with IDD.** For individuals with IDD, both parents and siblings reported difficulties in conducting planning given the support needs of their family members with IDD. Specifically, they reported three support needs: maladaptive behavior (Burke et al., 2015; Rawson, 2010), aging (Coyle et al., 2014; Davys et al., 2015), and difficulty understanding mortality (Baumbusch, Mayer, Phinney, & Baumbusch, 2017). First, siblings feared that changes (e.g., changing the residential setting of an individual with IDD from the family home to a group home or the sibling’s home) would lead to increased maladaptive behaviors (Rawson, 2010). As such, they struggled with conducting future planning. The second support need was aging (Coyle et al., 2014). Age-related changes such as the onset of dementia or other conditions (e.g., falls and mobility challenges) could require the individual with IDD to need more supports and services. Thus, such changes would lead to additional caregiving responsibilities for families. Siblings reported struggling with future planning as age-related changes may disrupt any future plans. Lastly, parents and siblings avoided future planning because they struggled to discuss parental death with their family member with ID due to the family member’s limited understanding of death (Baumbusch et al., 2017; Davys et al., 2015).

**Conflicts between individuals with IDD and their family members.** Individuals with IDD reported conflicts and disagreements with their family members regarding the future (Morningstar et al., 1995). For example, individuals with IDD reported that their parents were strict and had control over their lives leading to conflicts. As a result, individuals with IDD reported frustration as they did not have control over their own lives. This finding aligned with a study by Burke et al. (2015) wherein siblings reported that their parents were overprotective of their adult offspring with IDD. For example, siblings reported that their brothers and sisters with IDD became more independent when parents were no longer providing caregiving. As future planning should reflect person-centered planning, disagreements between individuals with IDD and their family members were problematic.

**Sibling balancing own lives.** Four studies found that siblings struggled with balancing their own lives and their impending caregiving roles. This subtheme was only reported by siblings of individuals with IDD. Specifically, siblings struggled to take care of their own families (i.e., their offspring and aging parents) while also taking care of their brothers and sisters with IDD and/or conducting future planning (Rawson, 2010). When siblings had full-time jobs, had children at home, and had their own family issues, they struggled to engage in future planning for their brothers and sisters with IDD (Davys et al., 2015; Tozer & Atkin, 2015).

**Systemic barriers.** Systemic barriers were grouped into four subcategories: lack of qualified professionals, lack of options and resources, lack of funding, and difficulty with systems navigation.

#### **Lack of qualified professionals**

Families reported struggling to find qualified professionals to serve individuals with IDD. The lack of qualified professionals made it difficult for families to establish future plans. For example, professionals (i.e., attorney, financial planners, direct service providers) may not understand the needs of families of individuals with IDD (Campbell & Essex, 1994; Weeks et al., 2009) as well as the needs of adults with IDD (Gauthier-Boudreault et al., 2017; Hole et al., 2013). There may be two reasons for the lack of qualified professionals: lack of empathy and high turnover rate. Regarding the former, professionals may not be able to relate and understand the experience of parenting an individual with IDD (Young et al., 2018). Indeed, many parents have reported that professionals did not have empathy for their situations. In addition, several studies have documented the high turnover rate among professionals (e.g., respite care staff, social workers) in the service delivery system due to limited occupational benefits (e.g., low salary; Gilbert, Lankshear, & Petersen, 2008; Hole et al., 2013). Thus, many families may struggle to find and keep qualified professionals. Siblings also worried about the lack of qualified professionals especially due to high turnover (Tozer & Atkin, 2015). Without qualified professionals, families may feel that it is not worthwhile to conduct planning.

#### **Lack of options and resources**

Parents reported that the lack of options (e.g., programs, job supports) and resources in the community negatively impacted future planning (Burke et al., 2018; Gauthier-Boudreault et al., 2017; Gilbert et al., 2008; Herrema et al., 2017; Taggart et al., 2012). For example, Gauthier-Boudreault et al. (2017) found that the service delivery system provided either limited full-time daily programming or low-quality activities (e.g., babysitting). In addition, families often faced long waiting lists to access services (e.g., respite care, Gilbert et al., 2008; Hole et al., 2013). Because of the lack of options and resources, families reported not engaging in future planning (Burke et al., 2018).

#### **Lack of funding**

Both parents and siblings reported limited access to financial benefits. Without funding, families may have limited residential, employment, or respite options for future planning. For example, in the study by Burke et al. (2018), almost 50% of parents reported financial barriers to future planning. Further, parents were worried about state budget cuts that might reduce funding for disability services. Thus, it was common for families to experience stress in relation to financial issues leading to a reduced likelihood of conducting future planning (Coyle et al., 2014; Gilbert et al., 2008).

#### **Difficulty with system navigation**

Families frequently reported challenges in navigating the adult service delivery system. Most families reported not knowing what services were available due to difficulty with service delivery system navigation; without knowing the available options,

families reported that future planning may not be worthwhile. Parents reported feeling overwhelmed with navigating multiple systems (Hole et al., 2013; Petriwskyj et al., 2017); siblings reported not knowing where to seek information (Davys et al., 2015; Rawson, 2010). Notably, siblings were inexperienced in accessing legal and financial services due to minimal involvement in systems navigation (Rawson, 2010). Further, organizational changes or policy shifts also made it difficult for siblings to understand the service delivery system (Tozer & Atkin, 2015).

### **RQ3: Interventions and Instruments to Facilitate Future Planning**

To facilitate future planning among family members, researchers developed either intervention training programs (i.e., Bigby et al., 2002, *Options for Older Families*; Botsford & Rule, 2004; Craig & Cartwright, 2015, *Quality Living 10-Year Plan*; DaWalt et al., 2018, *Transitioning Together*; Heller & Caldwell, 2006, *Future is Now*; Smith et al., 1996) or instruments (Reilly & Conliffe, 2002). Regarding the former, the intervention programs targeted caregivers and their offspring with IDD. The length of these programs varied from 9 to 15 hours. Across the programs, topics included: (a) family support services, (b) independent living options, (c) legal/financial planning, (d) advocacy, (e) problem-solving strategies, and (f) self-determination of individuals with IDD.

Individuals with IDD and families reported positive outcomes from participating in the intervention programs. For example, parents who participated in future planning interventions demonstrated: increased knowledge and access to formal resources for planning (Bigby et al., 2002; DaWalt et al., 2018; Smith et al., 1996), reduced caregiving stress (Bigby et al., 2002; Heller & Caldwell, 2006; Reilly & Conliffe, 2002) and depressive symptoms (DaWalt et al., 2018), increased competency to plan for the future (Botsford & Rule, 2004; Craig & Cartwright, 2015), increased use of problem-solving strategies (DaWalt et al., 2018), and opportunities to interact with other parents with similar concerns (Smith et al., 1996). Also, parents were more likely to conduct definitive planning activities (DaWalt et al., 2018; Heller & Caldwell, 2006).

At the same time, individuals with IDD also benefitted from intervention programs. Benefits included: greater access to out-of-home day activities, extension of supportive networks, skill development, increased self-determination skills, and attention to neglected health issues (Bigby et al., 2002). DaWalt et al. (2018) demonstrated that the adults with ASD in the intervention (vs. waitlist-control) group improved in their frequencies of social interactions and levels of social engagement with peers. On the other hand, Heller and Caldwell (2006) were more focused on developing self-determination skills (e.g., daily choice making) of individuals with IDD. Their future planning intervention was co-facilitated by a self-advocate. The adults with IDD in the intervention (vs. waitlist-control) group demonstrated significantly improved self-determination skills.

Although not an intervention, Reilly and Conliffe (2002) developed a planning instrument called *What the Future Holds*. By using the instrument, families reported greater communication with regard to different quality of life domains. The

instrument also helped families to consider the logistics of future planning (e.g., when to start planning, where to focus planning efforts, and what questions to address during the planning process).

#### **RQ4: Benefits of Conducting Future Planning**

Three studies identified the benefits of future planning for families of adults with IDD.

Only one study identified the planning benefits for parents. Freedman et al. (1997) reported that parents who established long-term, residential plans (vs. no residential plans) had more positive well-being, less stress, and a greater sense of purpose in life. Further, parents who had either short-term or long-term residential plans (vs. no residential plans) achieved an out-of-home placement within three years. Similarly, two studies reported the benefits of conducting future planning for siblings. As many siblings anticipated their future caregiving responsibilities, siblings were willing to be caregivers and felt less stressed when their parents were engaged in future planning early (Coyle et al., 2014; Griffiths & Unger, 1994). Specifically, when siblings discussed future plans with their family members, they were more willing to be in charge of caregiving responsibilities (Griffiths & Unger, 1994).

#### **RQ5: Correlates of Future Planning**

**Individual with IDD characteristics.** The severity of the disability was associated with future planning. However, there were mixed findings regarding the nature of this relation (Burke et al., 2018; Freedman et al., 1997). Freedman et al. (1997) reported that when individuals with IDD had a mild or moderate ID (vs. severe or profound ID), parents were more likely to conduct future residential planning. In contrast, Burke et al. (2018) found that parents were more likely to engage in future planning when their offspring with IDD had fewer functional abilities. This difference might be due to measures. For example, Freedman et al. (1997) used a dichotomous item to gauge the level of ID (i.e., the response options were 0 [severe/profound] or 1 [mild/moderate]) while Burke et al. (2018) used the Activities of Daily Living Scale (Lawton, Moss, Fulcomer, & Kleban, 1982) to gauge the level of independence as a proxy for the severity of the disability. The dichotomous option may not offer much utility with respect to characterizing the needs of the individual with IDD. In contrast, the Activities of Daily Living scale was a 15-item scale with three response options providing a greater breadth of understanding the needs of the individual with IDD.

**Family characteristics.** In previous studies, researchers found correlates of future planning that related to family characteristics including: age and health status, participation in training activities, and family communication.

##### **Age and health status**

With respect to family characteristics, parent and sibling age mattered (Burke et al., 2018; Freedman et al., 1997; Heller &

Factor, 1993; Heller & Kramer, 2009; Smith et al., 1996). Specifically, future planning was positively correlated with sibling and parent age (Burke et al., 2018; Heller & Kramer, 2009). Similarly, when mothers had worse health or worse maternal well-being, they were more likely to conduct future planning (Freedman et al., 1997).

##### **Annual income status**

When parents had greater household incomes, they were more likely to conduct financial and residential planning (Heller & Factor, 1993).

##### **Marital status**

Only one study reported that when parents were unmarried, they were more likely to conduct residential planning (Freedman et al., 1997).

##### **Participation in training**

Families, who had a greater connection to the disability system or had greater participation in educational training about the adult service delivery system, were more likely to conduct future planning (Burke et al., 2018; Heller & Kramer, 2009).

##### **Family communication**

Greater family communication was positively correlated with future planning (Griffiths & Unger, 1994).

#### **Discussion**

To understand future planning among the families of individuals with IDD, a systematic literature review was conducted. There were four main findings. First, most family members had not made future plans. Of the individuals who engaged in future planning, it was often not comprehensive plans as the plans did not include diverse aspects of future planning. Additionally, most families reported conducting aspirational (vs. definitive) activities. Although the current state of future planning was uncomprehensive, many families reported the need to conduct future planning before a crisis occurs.

Second, families reported different types of barriers to future planning. Most barriers were consistent with a previous literature review about the barriers to future planning (Bibby, 2013). However, this literature review extended current research by identifying barriers from the perspectives of siblings and individuals with IDD. Interestingly, most siblings were not engaged in future planning despite the potential for impending caregiving roles. The lack of involvement may be due to siblings struggling to balance their own lives (i.e., work, marriage, and raising their own children). Moreover, individuals with IDD were often excluded from future planning (Morningstar et al., 1995). Given that few studies examined the perspectives of siblings and individuals with IDD with respect to future planning, more research is needed to understand the perspectives of each family member.

Third, few studies examined the benefits of future planning. Specifically, there were only five studies that developed and tested future planning interventions for families of individuals with IDD. In these studies, future planning facilitated positive

outcomes for individuals with IDD and their parents. Notably, there was no intervention study that targeted or included siblings of individuals with IDD in future planning. Given their future roles, future planning interventions should be adapted for siblings.

Lastly, five studies identified correlates of future planning. Correlates included the severity of the disability, age and health status of the parents and siblings, marital status, participation in trainings, and family communication. Among these correlates, it is necessary to highlight correlates that could be capitalized on in future planning interventions. For example, interventions which provide education about the disability system, improve family communication, offer peer support, and improve connections to the disability system may facilitate future planning.

It is important to acknowledge the limitations of this review. First, most studies included small sample sizes which were primarily White and female. More research is needed among diverse families (i.e., race, ethnicity, and socioeconomic status). Also, most survey studies relied on cross-sectional data (i.e., data were only collected at one time point). Thus, the results could not show the direction of any associations. For example, it cannot be inferred whether participation in a training caused greater future planning or whether greater future planning caused more participation in training. A longitudinal study would be able to identify predictors of future planning. As a final limitation, the quality of the studies and the impact of the year of the publication were not addressed in this review. Regarding the latter, the year of the publication of a study could impact its relevance today due to changing policies and the increasing lifespans of individuals with IDD.

## Directions for Future Research

Considering the benefits of conducting future planning, more intervention research is needed to facilitate future planning. In previous future planning interventions, most programs targeted parents of individuals with IDD (Heller & Caldwell, 2006). As a result, it is unknown whether siblings of individuals with IDD would also benefit from future planning interventions. There is a need to develop and test interventions for siblings including information and peer support as every family member needs to be in the process of future planning.

Future research is also needed to examine the perspectives of individuals with IDD with respect to their own future. In this review, only one study was solely conducted with individuals with IDD (Morningstar et al., 1995). As future planning should reflect person-centered planning, the voices of individuals with IDD are crucial. Thus, in the future, it is necessary to examine how individuals with IDD participate in future planning process.

Lastly, research is needed to compare future planning across different countries. Such research is important to understand how cultural values and location may impact the planning process. For example, Ireland (vs. the United States and the United Kingdom) offers limited guidance promoting person-centered approaches (Hasse & Byrne, 2005). This may result in future planning being less person-centered in Ireland (vs. other countries). In addition, public policy may impact planning. Indeed, in a review of five countries, public policy impacted services for

adults with ID (Bigby, 2010). Thus, future research should consider inter-country variation in future planning.

## Implications for Policy and Practice

Given that family caregivers face many barriers to provide life-long supports for their offspring with IDD, policymakers and practitioners need to offer supports (i.e., information, peer support group, future planning trainings) to family caregivers. Unfortunately, many families reported difficulty in conducting planning due to structural issues (i.e., lack of qualified staff, lack of program options, lack of funding). Thus, systemic supports need to be provided to families. Policymakers need to consider offering high-quality supports to individuals with IDD and their families.

Finally, practitioners should encourage families to communicate about future planning. One of the biggest barriers to planning was the lack of communication among family members regarding the future. Indeed, most future planning activities are conducted by parents. By encouraging the family as a unit to communicate with one another about the future, families may be able to conduct definitive planning activities. Further, given frequent organizational and policy changes, practitioners need to provide accessible information to families, especially families of different cultural and linguistic backgrounds who have language barriers, about available services.

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