Understanding Decision Making Among Individuals With Intellectual and Developmental Disabilities (IDD) and Their Siblings

Meghan M. Burke, Chung eun Lee, Sarah A. Hall, and Zach Rossetti

Abstract

Many siblings anticipate fulfilling caregiving roles for their brothers and sisters with intellectual and developmental disabilities (IDD). Given these roles and the importance of supported decision making, it is crucial to understand how individuals with IDD and their siblings make decisions. Using dyadic interviews, we examined the perspectives of nine sibling dyads ($N = 18$) about decision making in relation to self-determination, independent living, and employment. The ages of participants ranged from 19 to 57. Data were analyzed using constant comparative analysis to identify themes. Decision making was characterized by: parents and siblings primarily identifying courses of action; the probability of respective consequences based on the person-environment fit; and the role of the sibling in making the final decision. Characteristics related to the individual with IDD, the family, the sibling, and the environment impacted decision making. Individuals with IDD were more likely to make their own decisions about leisure activities; however, siblings were more likely to make formal decisions for their brothers and sisters.

Key Words: *sibling; decision making; families; self-determination*

Individuals with intellectual and developmental disabilities (IDD) are living longer, and the majority (84%) of adults with IDD live with their aging parents (Fujiura, 2010). The caregiving roles of aging parents are often transitioned to the siblings of individuals with IDD (Kramer, Hall, & Heller, 2013), a responsibility that is willingly embraced by many siblings (Orsmond & Seltzer, 2007). Because adult siblings have a profound impact on the lives of their brothers and sisters with IDD, it is crucial to examine how they make decisions.

Decision making is defined as making choices within a given context by: identifying courses of action, determining the probability of respective consequences, and choosing and implementing the best course of action (Hickson & Khemka, 2013). With respect to decision making among people with IDD, over the past decade, the supported decision-making approach has been gaining momentum wherein "adults with disabilities get help in making decisions but they retain control over who provides that help, and what the ultimate decisions will be" (Jameson et al., 2015, p. 38). In supported decision making, the individual with a disability chooses supporters to assist with decision making, and, in many cases, siblings are likely to be chosen as supporters. Despite the importance of siblings in the lives of people with IDD, there is a lack of evidence about supported decision making between adults with IDD and their siblings.

Past research about people with IDD and their siblings has focused on the perspectives of the siblings of individuals with IDD (for a review, see Taylor, Burke, Smith, & Hartley, 2016). For example, although 60% of siblings anticipate living with their brothers and sisters with IDD (Freedman, Krauss, & Seltzer, 1997), it is unclear whether individuals with IDD want to live with their siblings. Also, siblings have reported trying to secure employment for their brothers and sisters with IDD (Kramer et al., 2013). However, few studies have examined whether individuals with IDD want such employment. With respect to self-determination, siblings of individuals with IDD have reported advocating for their brothers and sisters with IDD (Burke, Arnold, & Owen, 2015). Yet, it is unclear whether siblings consider the self-

determination of their brothers and sisters with IDD in their advocacy efforts.

In light of the supported decision-making movement, a better understanding of the perspectives of people with IDD *and* their siblings about decision making is essential. The purpose of this study was to investigate how sibling dyads (i.e., the brother or sister—an adult with a disability and an adult sibling without a disability) make decisions regarding independent living, employment, and self-determination. This study was limited to sibling pairs, given the likelihood of siblings fulfilling caregiving roles (Kramer et. al, 2013).

At the most basic level, it is important to understand whether and, if so, how siblings facilitate the involvement of their brothers and sisters with IDD in decision making. In addition to understanding the decision-making process, it is important to identify the variables that influence decision making among sibling dyads. In alignment with supported decision making, Shogren and Wehmeyer (2015) identified factors that affect decision making: personal characteristics, environmental demands, and support needs. In one of the few investigations focused on decision making within families, Knox and Bigby (2007) conducted extensive interviews with five families of individuals with intellectual disability to understand family caregiving. In their study, parents guided most of the caregiving decisions. To a lesser extent, sibling life choices (e.g., marriage, having children) also impacted caregiving decisions. The current investigations build on the study by Knox and Bigby and the conceptual work of Shogren and Wehmeyer (2015) by investigating factors related to personal characteristics, environmental demands, and support needs that affect decision making among people with IDD and their siblings.

In addition to understanding the variables influencing decision making, it is also important to understand whether people with IDD and their siblings agree with the decisions and how disagreements are resolved. Gross, Wallace, Blue-Banning, Summers, and Turnbull (2012) conducted case studies with four families of adults with IDD about decisions regarding consumer-directed supports. Notably, adults with IDD were not included in the study. Participants reported that consumer-directed supports allowed their offspring with IDD to receive individualized services to achieve goals. Although an important first step, future researchers need to investigate the perspectives of people with IDD to better understand the relation between self-determination and decision making.

Self-determination is defined as "... acting as the causal agent in one's life" (Shogren et al., 2015, p. 258). In the context of decision making, supported decision making should result in self-determined decisions, given the key role of the individual with IDD. Because of the importance of self-determination, it is necessary to understand how people with IDD and their siblings make decisions together, including ways in which siblings facilitate the involvement of their brothers and sisters with IDD in decision making.

When people with IDD and their families are involved in decision making, individuals with IDD are more likely to receive services they want and their family members are more likely to be satisfied with services (Neely-Barnes, Marcenko, & Weber, 2008). In the current study, reports of decision making were examined with respect to a person with IDD's independent living, employment, and self-determination. Using the framework of supported decision making, this study had three research questions:

1. How do siblings and their brothers and sisters with IDD make decisions?
2. Which variables influence the decisions of sibling dyads?
3. What is the extent of agreement within such decisions?

Method

Dyadic interviews were conducted with nine sibling pairs. Dyadic interviews allow for a shared narrative of the sibling dyad (Arksey, 1996) and for analysis of sibling interactions (Morris, 2001). Specifically, for each sibling dyad, three interviews were conducted to ensure the validity of the data: an interview with the sibling, an interview with the individual with IDD, and a dyadic interview with the sibling and the individual with IDD. Social constructivism was used as the epistemological viewpoint because the purpose of this study was to construct perceptions about decision making. The qualitative research approach was phenomenology, specifically a qualitative interview methodology (Patton, 2002), to understand the lived experiences with respect to decision making of siblings and their brothers and sisters with IDD.

Participants

For siblings (i.e., individuals without IDD), the inclusionary criteria were: (1) be 18 years or older; (2) have a brother or sister with IDD who will participate in this research; and (3) be willing to participate in an interview and complete a demographic form. For individuals with IDD, the inclusionary criteria were: (1) be an individual who, according to sibling reports, was diagnosed with intellectual disability or a related developmental disability (IDD); (2) be 18 years or older; (3) have a sibling without IDD who was willing to participate in this research; (4) be willing to participate in an interview and complete a demographic form; and (5) have a functional system of communication as reported by the sibling. "Meaningful communication" was a synonym for having a functional communication system and was defined on the questionnaire as having a reliable method of communication that could include verbal ability, sign language, and augmentative and alternative communication devices. All of the participants with IDD used verbal language as their primary mode of communication.

Nine sibling pairs from Illinois, Ohio, and Massachusetts participated in this study. There were six female siblings with brothers with IDD, two female siblings with sisters with IDD, and one male sibling with a brother with IDD. Seven of the siblings were older and two were younger than their brother or sister with IDD. The siblings reported that their brothers and sisters with IDD had various types of primary diagnoses including: Down syndrome (DS), intellectual disability (ID), and autism spectrum disorder (ASD). Additional information about the participants with IDD and their siblings is provided in Table 1.

Regarding the housing status of the individuals with IDD, five participants lived with their parents, two participants lived in a supported home (e.g., Community Integrated Living Arrangement), and two participants lived alone (i.e., without other housemates). Each sibling lived in the same state as the respective brother or sister with IDD. With respect to parent involvement, seven dyads had living parents; for two dyads, their parents were deceased. All individuals with IDD had some daily activities. Specifically, six participants had some kind of employment and three participants attended postsecondary programs.

Recruitment

Participants were recruited in multiple ways. For example, information about the study was distributed via e-mails and flyers to statewide sibling organizations. The researchers also attended the Ohio Adult Sibling Conference to recruit participants and conduct interviews. Recruitment materials were also distributed via websites and shared by word of mouth. Recruitment e-mails and flyers included information about the study, research team, and the participant stipend. Interested individuals contacted the research team to participate in the study. Each participant received a $20 gift card for participating in the study.

Procedures

All recruitment and study procedures were approved by the institutional review board (IRB) of the first author; the affiliated university of the other authors accepted the IRB approval of the first author's university. Consent was obtained from all participants. Two participants had guardians, and the guardians for these participants also provided consent. To ensure that the consent form was accessible to participants with IDD, simplified language was used. Further, the consent form was provided to the participant as well as read aloud. While reading the consent form, the researcher checked for the participant's understanding.

Each interview occurred at a location, date, and time that was preferred by the participant. Specifically, interviews were held in participants' homes, coffee shops, libraries, and offices. After researchers explained the study and answered any questions, consent forms were signed, demographic forms were completed, and researchers then conducted audio-recorded interviews. The first author conducted interviews with two sibling pairs; the second author and third authors conducted interviews with three sibling pairs, respectively; and the fourth author conducted interviews with one sibling pair. To establish rapport, the same researcher conducted the three interviews (i.e., sibling, individual with IDD, and dyadic) with a sibling pair. Except for the dyadic interview, siblings were not present during each other's interview. Interviews lasted 45-75 minutes and 25-60 minutes for interviews with siblings and individuals with IDD, respectively. The dyadic interviews lasted 20-45 minutes.

Table 1
Participant Demographics

Sibling Dyad	Age	Gender	State	Education	Ethnicity	Primary Diagnoses
1. Eli	44	M	OH	Some college	White	DS
1. Nicole	47	F	OH	Some college	White	—
2. Emma	38	F	IL	Some college	White	DS
2. Anna	41	F	IL	Graduate school	White	—
3. Roy	24	M	IL	Some college	White	DS
3. Jane	29	F	IL	College	White	—
4. Jason	49	M	OH	High school	White	DS
4. David	55	M	OH	College	White	—
5. Mallory	19	F	OH	High school	White	DS
5. Cara	22	F	OH	Some college	White	—
6. Neil	56	M	OH	None	AA	ID
6. Tashelle	57	F	OH	Graduate school	AA	—
7. Aaron	33	M	IL	High school	White	ASD
7. Rachel	30	F	IL	Graduate School	White	—
8. Cameron	21	M	IL	High school	White	ASD
8. Allison	30	F	IL	College	White	—
9. Anthony	36	M	MA	High school	White	ASD
9. Sara	30	F	MA	Graduate school	White	—

Note. AA = African American; ASD = Autism spectrum disorder; DS = Down syndrome; ID = Intellectual disability; IL = Illinois; MA = Massachusetts; OH = Ohio.

Notably, the siblings without disabilities were interviewed first, followed by interviews with individuals with IDD, and concluding with the dyadic interviews. Information from the first interview with the sibling without a disability was used to facilitate the interview with the individual with IDD. Such information included the best ways to communicate with the individuals with IDD. Also, information from the first interview was used to create probing questions for the interview with the individual with IDD. By having individualized probes for the individual with IDD, more in-depth responses could be given by the individual with IDD.

For the individuals with IDD, accommodations were made to ensure the validity of the interview (Hall, 2013). For example, before the interview, the researchers established rapport with the individual with IDD by asking simple, personal interest questions (e.g., "What do you like to do?" and "What do you do with your sibling?"). Depending on the needs of the individual with IDD, the researcher helped the individual complete the demographic form by recording their verbal re-sponses to the questions. Also, the interview protocol included plain language. During the interview, the researcher used short and simple questions, rephrased questions to allow for understanding, and allowed extra response time (Mactavish, Lutfiyya, & Mahon, 2000).

If deemed necessary by the sibling and/or the individual with IDD, pictures were used to increase the accessibility of the interview questions. For example, a participant with IDD brought two scrapbooks to share her experiences. The photographs reminded her of work experiences to share and provided us (i.e., the researchers) with a better understanding of her experiences. Individuals with IDD could also choose a support person to attend the interview with them (Mactavish et al., 2000). Only one participant with IDD asked her mother to provide support.

Interview Protocol
The research team developed a semistructured interview protocol by reviewing the literature about adult siblings of individuals with IDD (e.g., Burke, Arnold et al., 2015; Kramer et al., 2013). By using

semistructured interview protocols, the interviews were equally directed by the researcher and the participant (Taylor & Bogdan, 1998). Further, participants were able to respond to open-ended questions, thereby providing information about decision making. The protocol focused on housing, employment, and self-determination, as these are critical areas of decision making (e.g., future planning) for individuals with IDD (Heller & Caldwell, 2006). To ensure the content validity of the protocol, two experts in sibling research reviewed the protocol and the protocol was revised in accordance with their feedback. The protocol was also piloted with two sibling pairs. The pilot interview data were not included in this study. From the pilot, the protocol was revised by making minor grammatical and wording changes. For each sibling pair, the interviews were conducted back-to-back and on the same day. Each of the questions in the semistructured interview protocol was asked of all participants. At the end of each interview, the researcher provided a synthesis of what was discussed to informally member check the information provided from the interview (see Table 2).

All interviews were transcribed verbatim. The researcher who conducted the interview reviewed each transcription for accuracy. During and after the interview, each researcher recorded detailed field notes capturing observational data about sibling interactions during the interviews, responses, and other data relevant to the research questions. The researchers also held biweekly conference calls to discuss all research activities, especially data collection and emerging themes. Notes from these conference calls were written as researcher memos and were included as data. From these conference calls, it was determined that saturation was reached with nine sibling dyads; as such, data collection ended.

Data Analysis

For this study, a thematic approach was used to organize and analyze data. Specifically, constant comparative analysis and emergent coding were used (Glaser & Strauss, 1967; Patton, 2002). First, the researchers read the transcripts individually to familiarize themselves with the data (Tesch, 1990). A line-by-line approach was used to independently open code each piece of text, noting any data that related to the research questions and extant literature. Although each coded text varied in size,

Table 2

Semistructured Interview Joint Protocol for Individuals With Disabilities and Siblings

Question Number	Question*
1.	Tell me a bit about yourselves: What do you and your sibling like to do together? What is your favorite thing about your sibling?
2.	How do you make choices about where to live? Who makes the choice? Will your sibling help you live there? How will your sibling help you?
3.	How do you make choices about jobs? Who makes this choice? Will your sibling help you get that job? How will your sibling help you?
4.	How do you make choices in general? Who makes the choices? Will your sibling help you make decisions? How will your sibling help you? Is there anything that you want to add?

Note. * Potential follow-up questions included: "Can you tell me more about that experience?" Potential probes included "That is interesting … can you tell me more about that?" and "Can you give me an example of that?"

each piece of text represented a single idea. Individually, each piece of data was compared to the previously coded data to determine whether the data represented a novel idea (Creswell, 2013). After open coding, the researchers compared the codes to come to a consensus and to organize the codes into categories. A codebook was developed that included groups of codes that answered the research questions. Using the codebook, each researcher independently reviewed data using the new codes.

During the thematic coding stage, the focus was on the broader level of themes (Braun & Clarke, 2006). Themes were identified by examining and discussing patterns in the data manifested by connections among codes and between the coding categories. The themes were reviewed for internal and external heterogeneity to ensure that there was evidence for strong connections among data within themes and clear distinctions between themes (Braun & Clarke, 2006). Thematic analysis led to identifying findings in regard to each research question as well as implications of the

findings. The final stage of analysis was the cross-case analysis of data within and across sibling pairs (i.e., cross-case; Patton, 2002).

Reflexivity

Each researcher was also the sibling of an individual with IDD, a fact that was disclosed at the beginning of each interview. Thus, each researcher brought an "insider" perspective to the interview (O'Toole, 2013), which may have helped establish rapport with the participants. Along with an insider perspective, each researcher also brought biases to the project. For example, each researcher had an advocacy stance believing that people with IDD should participate in all facets of decision making (Creswell, 2013). To this end, the researchers engaged in reflexivity by discussing their own experiences and beliefs, as well as continually reflecting and documenting reflections from data collection to analysis.

Trustworthiness and Credibility

To establish credibility and trustworthiness, this study met several of the quality indicators outlined by Brantlinger, Jimenez, Klingner, Pugach, & Richardson (2005). For example, data were triangulated across data sources (e.g., demographic forms, interview transcripts); further, there was investigator triangulation by having multiple researchers and peer debriefing. After establishing the themes, negative case analysis was used to identify outliers (Brantlinger et al., 2005). To this end, the full range of data was included to show the diversity of responses.

To confirm the findings, the researchers debriefed with each other and conducted member checking (Lincoln & Guba, 1985). Member checking comprised of two levels. First, each researcher informally member checked their impressions of the data at the conclusion of every interview. At the second level, the researchers e-mailed a summary of each interview to the participants and asked them to complete a web-based form to validate, add, or change any themes. For the participants with IDD, the researchers also called the participants and explained the summary using plain language. This two-level member check process has been successfully used in other studies about families of people with IDD (e.g., Burke et al., in press). All participants completed member checking; no significant changes were suggested.

In addition, this was a collaborative work across four researchers who designed and conducted this study. Further, an audit trail was produced detailing the times and dates of the interviews and corresponding documents. This study also includes prolonged field engagement by collecting data from each participant three times (i.e., individual interview, dyadic interview, and member checking). In the Findings section and in Table 3 there are quotes and corresponding descriptions to provide evidence for the conclusions.

With respect to interview studies specifically and data analysis, this study also met each quality indicator as noted by Brantlinger and colleagues (2005). Appropriate participants were selected by recruiting sufficient participants who reflected the population of interest (i.e., people with IDD and their siblings). The interview questions were reasonable as determined by the piloting and the review by sibling experts. All interviews were recorded and transcribed verbatim; further, each researcher cross-checked the transcription and the audiotape to ensure accuracy. The findings from each participant are reported; pseudonyms are used to protect their confidentiality. Regarding data analysis, the systematic method used to sort and code data is described. Also described are the methods to establish trustworthiness and researcher reflexivity, as well as methods to check researcher biases. Finally, the quotations from participants were triangulated with the demographic information and field notes.

Findings

The Decision-Making Process

Hickson and Khemka (2013) characterized the decision-making process by: identifying courses of action, determining the probability of respective consequences, and choosing and implementing the best course of action. In this study, sibling pairs reported aligning with these steps. Specifically, sibling pairs engaged in decision making through: (a) parents and siblings primarily identifying courses of action, (b) the probability of respective consequences based on the person-environment fit, and (c) the role of the sibling in making final decisions (see Figure 1).

Parents and Siblings Primarily Identify Courses of Action. Many of the siblings reported that either parents or the siblings identified courses of action for decisions *for* their brother and sisters

Table 3
Quotes Based on Themes

Research question	Theme	Quotes
Decision-making process	Parents and siblings primarily identify courses of action	• Rachel, the sibling of a 33-year-old brother with ASD, described, "Yeah, me, my mom and my sister [without IDD] we all kind of really made decisions together . . . [We then] presented it in a light where he [Aaron] would think it would be a good idea."
		• Jason, with DS, reported, "I asked my brother and he is looking up my place [for me to live in the future]. So I then [look at the] first one, and second one, and it's too big and too small. So I am looking for something different." Researcher: "So you guys look together?" Jason: "Yea. We did."
	Probability of respective consequences based on the person-environment fit	• Jane described past employment opportunities for her brother, Roy, with DS: "He was an intern at a bank before. And he was an intern with a teacher . . . He really liked the bank one. We are having trouble looking for another internship."
		• Sara asked her brother Anthony, who had ASD, "Did you like living with [roommates] Becca and Mary?" Anthony: "At first. At first. But because there was like . . . because they were set in their ways . . . I think I was very pretty up for change."
	The role of the sibling in making the final decision	• Rachel, the sibling of a brother with ASD, explained when making final decisions: "We all have very different views on things. I think that [my mom] thinks that he's not as capable as he is. But I think because I spent day in and day out of doing this, I know that he's capable of more."
		• Researcher: "So have you guys talked about other jobs? Where you could stack shelves maybe in a different place? Or not?" David (sibling): "We really haven't talked about it too much. We can." Jason (brother with ID): "I wanna work at Meijer." David: "You wanna go work at Meijer?" Jason: "Yes." David: "You want to work closer to home?" Jason: "Yes." David: "Oh I'll check it out."
Variables impacting decision making	Family dynamics	• Allison described potential housing options for her brother with ASD: "It really depends on the timing. What is going on in our lives? Where are we working? Where are we living?"
		• Researcher: "Okay. If you want to live in a condo with roommates, who make this choice?" Roy [23-year-old with DS]: "I think my parents and Jane [sibling] too."

(Table 3 continued)

Table 3
Continued

Research question	Theme	Quotes
	Sibling relationship	• Sara, who had a brother with ASD, reported: "I don't have a good sense especially now that I have been living away from him for a while. I don't have a good sense of what he is able or unable or not able to do. What I hear from my parents is mostly stuff that he is not able to do."
		• Neil and Tashelle described their close sibling relationship. Researcher: "What do you like about her?" Neil: "She's my best, my best, my best, my best lady." Tashelle: "You know, at church he'll say things like, ladies and gentlemen, my beautiful queen—my sister."
	Individual skills and characteristics	• Allison, whose brother has ASD, reported: "He can do most things by himself. It's more just along the lines that we want to make sure that no one takes advantage of him. That's the only concern we really have. Cameron can very easily live on his own but if somebody came and started talking to him or they could easily get into his apartment, take money, and do something and then it's like what do we do?"
		• Neil, a 56-year-old with ID, described his living skills in his group home: "I clean dishes, I pick up. And mop and sweeping the floor … I wash. I wash clothes. I do it all by myself."
	Services and supports	• Tashelle described the impact of the lack of qualified staff, "The program director is supposed to make sure that a month before the member's IDs are expiring, that they get replaced. Well, there was a big issue with the program director here. She was stealing money from the men. And, it ended up going to court. So, she didn't renew his ID."
		• Jason, a 49-year-old with DS, described getting support from case worker, "My case worker … Her name is Sandy. She helps me a lot find my real job. So I did. So I shine silverware, wrap them, tie up, eat a little bit, and drink."
	Types of decisions, degree of agreement	• Jane described informal decisions about her brother, Roy, with DS. Researcher: "What choices does Roy make?" Jane: "Yes, he mostly makes choices about sleepovers or food."
		• Jane expressed concern about Roy's preference to live on his own. Jane: "I didn't know that you want to move out of mom and dad's house." Roy: "I do [want] to now." Jane: "You do now? But do you want to [move out]?" Roy: "Yes." Jane: "I think it switches … because I don't think he really knows of the big responsibilities he would have to move out of the basement with your TV."

Note. ASD = Autism spectrum disorder; IDD = Intellectual and developmental disabilities; DS = Down syndrome; ID = Intellectual disability.
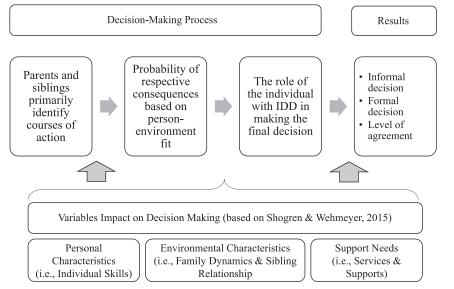
Figure 1. Decision-making process. IDD = intellectual and developmental disabilities.

with IDD. Sara, who had a 36-year-old brother with ASD, shared, "I don't know how much they [parents] get his [Anthony's] input … it's not a group decision. It's their decisions and I have some input." Individuals with IDD also reported that their families made decisions for them. Roy, a 23-year-old man with IDD along with four siblings and two living parents, discussed decision making in relation to housing:

> Researcher: So, who will help you decide where to live?
> Roy: Really—it is really my parents.
> Researcher: What did you do to learn about your living options?
> Roy: I don't know. I just know it from my mom.

The degree to which families sought the input of the individuals with IDD varied. Cara, the sister of a 19-year-old with a disability, reported, "It's probably more of, um, like, us trying to brainstorm things for her [Mallory], and then having her try them, and I guess, like, seeing how she reacts." Siblings without disabilities reported that they based their decisions on their perceptions of the interests and needs of their brothers and sisters.

Notably, two sibling pairs identified courses of action *with* their brothers and sisters with IDD. With respect to Emma, her 38-year-old sister, Anna explained how their family investigated various living options: "So, I called and made the appointments, and set them up. And then, the typical kind of road show is me, Emma, and my mom would go together and talk to different agencies." Anna, a professional in the disability field, included Emma and their parents in formal decisions.

The probability of respective consequences based on the person-environment fit. During the decision-making process, siblings reported making decisions based on their perceptions of the match between the preferences and needs of their brothers and sisters with IDD and available services and supports (i.e., the environment). Regarding employment, siblings reported that they considered the match between respective job sites and the needs, skills, and interests of their brothers and sisters with IDD. Allison, who had recently moved back into the family home with Cameron, her 21-year-old brother, reported "We are trying to think of a job that he [Cameron] could have, which I have some ideas of what he can do based on the times I've volunteered with him." Some participants with IDD had been successfully employed for several years after such efforts. For example, Emma worked in a grocery store. She confirmed the quality of her job match, explaining, "I love my job. [The grocery store] is a big place and [I] meet new people."

Siblings reported that striving for this person-environment fit required navigating the adult service delivery system. To identify the best fit for employment and the most appropriate housing option, siblings described needing knowledge of multiple service delivery systems and time to explore options. Deficits in these areas often complicated decision making. Drawing on her experience as a sibling, a professional in the disability field, and a social worker, Anna explained, "The challenge is making that happen. There's so many systems to navigate, and waiting lists, and paperwork, and finding the right person. It's tricky for us."

The role of the sibling in making the final decision. Siblings reported active involvement in making the final decision by advocating for their brothers and sisters with IDD within the family, advising parents, and attending service meetings. Most often, siblings reported that their advocacy stemmed from siblings (versus parents) having higher expectations for their brothers and sisters with IDD. For example, Cara reported that her 19-year-old sister, Mallory, was more capable than she appeared. Cara explained,

> My mom tried to answer and I was like, "No, no, give her [Mallory] a second," and sure enough, she did [answer] eventually. So I was like, "See, you just have to give her a minute to think and then it'll be fine."

Siblings also reported engaging in advocacy by relaying the perspectives of their brothers and sisters with IDD to their parents. Specifically, siblings reported sharing unique information about their brothers and sisters with IDD to help ensure person-centeredness in decision making. For example, Jane reported that her 24-year-old brother, Roy, wanted to live independently near his four siblings, yet their parents were looking into group homes. Jane alerted their parents to Roy's opinion:

> When my parents started a group home thing, I was kind of shocked. I was like, "Have you asked Roy what he wanted?" because Roy doesn't want that. So that's when they finally—I don't know because of me or what—but they took Roy into consideration.

Notably, in his individual interview, Roy reported wanting to live alone but shared that he had never discussed it with his parents or with his siblings:

> Researcher: Have you talked about wanting to live alone in the future with your parents?
> Roy: No.
> Researcher: What about with your siblings?
> Roy: Not yet.

Variables Impacting Decision Making

The participants described four factors that affected decision making: family dynamics, sibling relationship characteristics, individual skills and characteristics, and services and supports.

Family dynamics. A key factor related to decision making was parent involvement. Specifically, parent involvement affected the nature of decision making and the involvement of the individuals with IDD. In regard to her brother, Rachel explained: "Because my mom's his guardian, a lot of things aren't his decision." Some participants reported that their parents were overprotective of their brothers and sisters with IDD, and conflicts arose when making decisions due to differences in parent and sibling perspectives. Nicole described arguments with her mother about recreational decisions for her brother, Eli. Nicole shared that her mother registered Eli for recreational programs without his consent and, sometimes, Eli refused to go. Nicole defended Eli's decision.

> Eli will say "I just don't wanna go." So it's like "Ok." And that's a new behavior for my mom. Because she is like, "Oh no. You gotta go. Come on! You said you are gonna go, you gotta go." And I'm like, over the past three or four years, "Mom, when the man doesn't wanna go, don't make him go." You know? … Yeah. Absolutely, there is conflict.

Sibling relationship characteristics. The nature and dynamics of the sibling relationship influenced decision making. For example, the siblings' proximity to their brothers and sisters with IDD impacted decision making. Cara and Sara did not live near their siblings with IDD, and they described only being able to provide input from afar through phone conversations and text messages. Conversely, Allison recently moved back into the family home from a different state to be more involved in decision making with her brother. Additionally, Emma and her parents recently moved from their home state to the state in which

her sister without disabilities, Anna, lived as a means to facilitate decision making.

The communication style of the siblings and their brothers and sisters with IDD also affected decision making. Several siblings reported that they encouraged their brothers and sisters to make decisions by providing reassurance to help their brothers and sisters make choices, modeling choice making, and helping provide direction when making choices. As Nicole, a 47-year-old sibling with a brother with a disability, explained, "I just think it is so incredibly important to at least ask the questions. We can't assume. How are we gonna know if we don't ask?" As revealed in the next section, Nicole's emphasis on asking questions and insistence on seeking input from their brothers or sisters was not shared by all of the siblings.

Individual skills and characteristics. The abilities, personalities, and perspectives of both the individuals with IDD and their siblings influenced decision making. For example, several siblings reported that their perceptions of the cognitive abilities of their brothers and sisters with IDD impacted decision making. Specifically, Rachel reported that the cognitive disability of her brother, Aaron, prevented him from making decisions:

> Researcher: How do you think self-determination applies to Aaron?
> Rachel: It doesn't. I don't think he is aware enough to make decisions … Well, he will make decisions, but he has no idea what he is determining. They are bad decisions.

Tashelle, questioned her brother's (Neil) ability to make decisions, reporting that because he says that he likes everything, she feels comfortable making formal decisions for him:

> I would be the one making decisions for him. Some things I would engage him on, you know, the more mundane things … But in terms of, uh, "Do you want to see this doctor versus that doctor?" No.

The decision making of the siblings without disabilities was also affected by their personalities and other characteristics. Several siblings worked in the disability field and were able to utilize their knowledge of systems and professional networks within the decision-making process. For example, Anna worked in the disability field for over a

decade. She contacted multiple community agencies beyond the traditional providers on Emma's behalf. She explained, "I know the agencies, and I've got that social worker perception." Rachel and her sister without IDD both worked in the disability field. They strove to maximize their brother's access to supports that would promote his opportunities for independent living. At the same time, Rachel struggled to allow Aaron to make his own decisions, especially decisions she felt negatively affected his hygiene and health:

> I want him to make like the right choices. Like today at lunch, I was like "Why do you have a beard?" and he's like, "It's my choice! I want to!" I'm like, "Yeah, I guess you're right." Like I wish he would make the choice to not have one, but it is his choice. So he does make choices. Not good ones.

Services and supports. Participants reported that environmental variables, including the availability and quality of services and supports, influenced decision making. Involvement in decision making increased and was less complicated when appropriate services and supports were provided. Accessing services and supports allowed people with IDD to access greater opportunities and pursue their preferences. Anthony, a 36-year-old with a disability, discussed the supports he received at the grocery store where he worked: "Wegman's is a great place to work … they have been really enthusiastic about helping people with disabilities … and the support group there it is just amazing." The importance of services and supports in decision making was concisely summarized by Jason, who explained, "All my staff helps me a little bit."

Conversely, the lack of appropriate and effective services and supports reduced the decision-making ability of sibling pairs. With respect to the lack of housing supports and decision making, Jason's brother, David, reported:

> His [Jason's] dream is to have a place on his own. And you know, given his circumstance, and the waiver world, he needs to have a HUD property. He hasn't moved up on the list much over the last four or five years just because the people with physical disabilities get first priority, which makes sense. So, he has to wait.

Because of the lack of available services and the waiting list, David reported that Jason may be stuck on the waiting list indefinitely, and it is uncertain if he will ever be able to move into a home of his own.

Types of Decisions and Degree of Agreement

All of the participants with IDD made their own decisions about daily choices (e.g., what to eat, what to wear) and recreational activities (e.g., whether to visit a sibling's house). For example, Aaron, explained the daily decisions he made: "Well, as you can tell, the clothes I wear and I choose what I eat for breakfast and I choose what I eat for lunch." However, participants with IDD were far less involved in formal decision making (e.g., employment, housing). To this end, many siblings reported that their brothers and sisters needed support to make formal decisions. Some siblings reported that their brothers and sisters with IDD were "people pleasers" and, as such, could not make formal decisions. For example, Allison reported that her brother, Cameron, "wants to please everybody and make sure everyone is happy, which is good . . . [but] he would easily get swayed." Cara reported,

> She [Mallory] does tend to be pretty easygoing, which obviously is a good trait, but she's also kind of like, "Yeah, whatever happens, happens." . . . And we're like, "No." (laughs) So I think that's, like, getting her to feel some responsibility, I guess, for making choices.

Several siblings emphasized wanting their brothers and sisters with IDD to advocate for themselves during decision making. Jane explained of her brother, Roy, "I want him to speak his mind more because I think a lot of times he just gets frustrated and goes with the flow. I want him to actually tell us what he wants." Similarly, Sara, when speaking of her brother (Anthony), explained, "I don't know if he would know how to start looking for employment. I think if I directed him in the right place, he would click around and find some stuff, but I am not sure he has the follow-through to go through everything on it. So, he would need some supports in that."

Some individuals with IDD emphasized the importance of self-advocacy. Emma completed a postsecondary program and had been married; she was currently in a long-term relationship. She reported, "I want to teach them [other individuals with disabilities] to be a strong advocate. Um . . . stop putting yourself down, and also, to make their own choices . . . instead of relying on their parents."

Regarding the level of agreement in decision making, there were several instances in which there were conflicting viewpoints. For example, Nicole planned to move into the family home with Eli and said that she included Eli in this decision. Yet, there were other instances where Eli was not involved in decision making. For example,

> Nicole: I wanna be his caregiver in the future. It [the group home waiting list] is plan B.
> Researcher: Does he [Eli] know that he is on the waiting list?
> Nicole: No.

So, although Nicole reported that Eli was included in all decision-making activities, he did not know that he was on the waiting list for a group home. Further, when Eli was asked with whom he wanted to live, he stated that he wanted to live with his brother, Ryan. Another example of conflicting perspectives involves Emma and Anna. At the time of the interview, Emma had a long-term boyfriend. However, Anna stated that they did not have a serious relationship. Yet, in the dyadic interview, Emma and Anna reported:

> Emma: Actually, me and John [boyfriend] want to be together and John has been talking to me about finding an apartment to be together.
> Anna: Oh, I didn't know that you guys are talking about that.
> Emma: In the future, he wants to call me his wife. It is almost two years, next November.
> Anna: Two years. Yeah. I know you always think about your future, right? . . . Well, I guess we've never really talked about that, Emma. I guess it is new information to me. So I guess we have to think about it.

Discussion

This study contributes to the literature by presenting the perspectives of people with IDD and their siblings regarding decision making. We had four main findings. First, we found that, although

individuals with IDD made their own recreational and leisure decisions, most of the more formal decision making was done by siblings and parents. Although supported decision making is becoming more popular, the individuals with IDD in our study were not making formal decisions about their lives. Especially given that people with IDD may have different plans and preferences than their siblings, it is necessary to embrace a process that places people with IDD in the driver's seat in regard to decision making about their lives.

Second, although siblings reported advocating for their brothers and sisters with IDD to be included in decision making, siblings also reported the need to increase the self-determination of their brothers and sisters with IDD. Currently, there are several evidence-based practices to increase self-determination among people with IDD. In a review of self-determination interventions, Wood, Fowler, Uphold, and Test (2005) identified 21 studies; however, only 9.5% (n = 2) of the interventions occurred in the family home. Such interventions need to be available to families who want to support the development of self-determination skills in family members with IDD.

Third, siblings and their brothers and sisters with IDD were not always in agreement about decisions. Thus, it did not seem that siblings were using supported decision making, as they were not always supporting the decisions of the brother or sister with IDD. This point is especially important given that most sibling studies only reflect the viewpoint of the sibling without IDD (Hodapp, Glidden, & Kaiser, 2005). By only including the perspective of the sibling without IDD in research, we may be missing the nuance and, perhaps, the accuracy of a phenomenon (e.g., decision making). Further, this finding extends the extant literature by demonstrating that there are disagreements within families about decision making. Previous studies have similarly demonstrated that disagreements may exist between the individual with IDD and their parents related to self-determination, as well as between parents and siblings regarding caregiving roles (Hewitt, Agosta, Heller, Williams, & Reinke, 2013). Future research needs to focus on ways to promote the positive resolution of disagreements among family members, especially in regard to major life decisions affecting the member with the disability.

Finally, consistent with prior research about decision making (Shogren & Wehmeyer, 2015),

three factors impacted decision making: personal characteristics (e.g., perceived capacity); environmental demands (e.g., lack of available services); and support needs (e.g., need to increase self-determination). The phenomenon of decision making does not seem limited to the desires of people with IDD and their families but, rather, also depends on available services and supports. Additionally, previous research among siblings of people with IDD has consistently documented that siblings report needing information about adult services (e.g., Arnold, Heller, & Kramer, 2012; Holl & Morano, 2014). Thus, when thinking of creating interventions to facilitate decision making, the context of the service delivery system must be addressed in addition to family dynamics.

This study had several limitations. Our recruitment may have been more likely to reach highly involved siblings, and the perceptions and experiences of highly involved siblings might be different than others. Further, our study included individuals with IDD who had strong verbal skills; their communication (and our understanding) of their wants, needs, and preferences was not a barrier. Individuals with IDD with more signification communication challenges might have different experiences. Also, it would have been helpful to have observations of decision making to illuminate the decision-making process. Finally, although we collected rich data from each participant three times (i.e., individual interview, dyadic interview, and member checking) and in different formats (e.g., demographic sheet and interview), we did not align with Seidman's (2006) three interview process. To fully align with Seidman's process, we would have needed to conduct three (versus two) separate interviews with each participant.

Directions for Future Research

This study clearly points to the need for family research to include the perspectives of individuals with IDD and their siblings and parents. Most of the family research about people with IDD focuses on only one family member, often the mother (Taylor et al., 2016). Although this study recognized that parent involvement was crucial to decision making, this study also indicated that other family members, including individuals with IDD, may hold different perspectives than parents. For example, this study confirmed previous research (Burke, Fish, & Lawton, 2015) that siblings

perceive their parents as overprotective of their family members with IDD. This study also confirmed that family members (i.e., siblings) may have different opinions than the individuals with IDD (Hewitt et al., 2013). It seems that one family member cannot serve as a proxy for the perspective of an individual with IDD.

Another direction for future research is the need to develop and test a supported decision-making intervention. In our study, the dyadic interviews offered a forum for people with IDD and their siblings to share their unique perspectives, find a common ground, and begin to make decisions. Based on our study, it seems that future researchers should develop supported decision-making interventions with both the individual with IDD and the sibling present (as well as other supporters). To date, a few interventions exist involving the individual with IDD and the family. For example, Heller and Caldwell (2006) developed and tested the "Future is Now" training, wherein individuals with IDD and their family members attended a training about future planning. Most of the family members in their study, however, were parents (not siblings). Future researchers should consider developing and testing supported decision-making interventions with an approach that includes parents, siblings, and individuals with IDD.

Implications for Practice

Practitioners need to ensure that siblings and their brothers and sisters with IDD are involved in decision making. Based on this study, siblings may have unique perspectives (e.g., higher expectations) and important roles (e.g., advocates). Because of these perspectives and roles combined with the potential for becoming caregivers (Orsmond & Seltzer, 2007), it is critical that practitioners include siblings in decision making. However, including the sibling perspective in decision making is insufficient. Practitioners also need to include the individual with IDD in decision making. Siblings cannot be used as a proxy for the individual with IDD.

Practitioners should also consider the impact of services on decision making. As noted in this study, the availability of quality and appropriate services facilitated or hindered decision making. Given that the adult service delivery system is ill-equipped to meet the needs of people with IDD (Research and

Training Center on Community Living, 2013), practitioners should consider identifying natural supports and services to complement formal services. Together, informal and formal services may facilitate decision making because people will have more options to consider.

References

Arksey, H. (1996). Collecting data through joint interviews. *Social Research Update, 15*. http://sru.soc.surrey.ac.uk/SRU15.html

Arnold, C. K., Heller, T., & Kramer, J. (2012). Support needs of siblings of people with developmental disabilities. *Intellectual and Developmental Disabilities, 50*(5), 373–382. http://dx.doi.org/10.1352/1934-9556-50.5.373

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children, 71*(2), 195–207. http://dx.doi.org/10.1177/001440290507100205

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. http://dx.doi.org/10.1191/1478088706qp063oa

Burke, M. M., Arnold, C. K., & Owen, A. L. (2015). Sibling advocacy: Perspectives about advocacy from siblings of individuals with intellectual and developmental disabilities. *Inclusion, 3*(3), 162–175. http://dx.doi.org/10.1352/2326-6988-3.3.162

Burke, M. M., Fish, T., & Lawton, K. (2015). A comparative analysis of adult siblings' perceptions toward caregiving. *Intellectual and Developmental Disabilities, 53*, 143–157. http://dx.doi.org/10.1352/1934-9556-53.2.143

Burke, M. M., Meadan-Kaplansky, H., Patton, K. A., Pearson, J. N., Cummings, K. P., & Lee, C. (in press). Advocacy for children with social-communication needs: Perspectives from parents and school professionals. *Journal of Special Education.*

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches.* Thousand Oaks, CA: Sage Publications, Ltd.

Freedman, R. I., Krauss, M. W., & Seltzer, M. M. (1997). Aging parents' residential plans for adult children with mental retardation. *Mental Retardation, 35*, 114–123. http://dx.doi.org/10.

1352/0047-6765(1997)035%3C0114:APRPFA%3E2.0.CO;2

Fujiura, G. T. (2010). Aging families and the demographics of family financial support of adults with disabilities. *Journal of Disability Policy Studies, 20*(4), 241–250. http://dx.doi.org/10.1177/1044207309350560

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research.* Chicago, IL: Aldine.

Gross, J. M., Wallace, L., Blue-Banning, M., Summers, J.A., & Turnbull, A. (2012). Examining the experiences and decisions of parents/guardians: Participant directing the supports and services of adults with significant intellectual and developmental disabilities. *Journal of Disability Policy, 24*(2), 88–101. http://dx.doi.org/10.1177/1044207312439102

Hall, S. A. (2013). Including people with intellectual disabilities in qualitative research. *Journal of Ethnographic & Qualitative Research, 7*(3), 128–142. https://eric.ed.gov/?id=EJ1015434

Heller, T., & Caldwell, J. (2006). Supporting aging caregivers and adults with developmental disabilities in future planning. *Mental Retardation, 44*(3), 189–202. http://dx.doi.org/10.1352/0047-6765(2006)44%5B189:SACAAW%5D2.0.CO;2

Hewitt, A., Agosta, J., Heller, T., Williams, A. C., & Reinke, J. (2013). Families of individuals with intellectual and developmental disabilities: Policy, funding, services, and experiences. *Intellectual and Developmental disabilities, 51*(5), 349–359. http://dx.doi.org/10.1352/1934-9556-51.5.349

Hickson, L., & Khemka, I. (2013). Problem solving and decision making. In M. Wehmeyer (Ed.), *The Oxford handbook of positive psychology and disability.* New York, NY: Oxford University Press.

Hodapp, R. M., Glidden, L. M., & Kaiser, A. P. (2005). Siblings of persons with disabilities: Toward a research agenda. *Mental Retardation, 43,* 334–338.

Holl, E., & Morano, C. L. (2014). Supporting the next generation of caregivers: Service use and needs of adult siblings of individuals with intellectual disability. *Inclusion, 2*(1), 2–16. http://dx.doi.org/10.1352/2326-6988-2.1.2

Jameson, J. M., Riesen, T., Polychronis, S., Trader, B., Mizner, S., Martinis, J., & Hoyle, D. (2015). Guardianship and the potential of supported decision making with individuals with disabilities. *Research and Practice for Persons with Severe Disabilities, 40*(1), 36–51. http://dx.doi.org/10.1177/1540796915586189

Knox, M., & Bigby, C. (2007). Moving towards midlife care as negotiated family business: Accounts of people with intellectual disabilities and their families "just getting along with their lives together." *International Journal of Disability, Development and Education, 54*(3), 287–304. http://dx.doi.org/10.1080/10349120701488749

Kramer, J., Hall, A., & Heller, T. (2013). Reciprocity and social capital in sibling relationships of people with disabilities. *Intellectual and Developmental Disabilities, 51*(6), 482–495. http://dx.doi.org/10.1352/1934-9556-51.6.482

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic enquiry.* Thousand Oaks, California: Sage.

Mactavish, J., Lutfiyya, Z., & Mahon, M. (2000). "I can speak for myself": Involving individuals with intellectual disabilities as research participants. *Mental Retardation, 38*(3), 216–227. http://dx.doi.org/10.1352/0047-6765(2000)038%3C0216:ICSFMI%3E2.0.CO;2

Morris, S. (2001). Joint and individual interviewing in the context of cancer. *Qualitative Health Research, 11*(4), 553–567. http://dx.doi.org/10.1177/104973201129119208

Neely-Barnes, S. L., Marcenko, M. O., & Weber, L. (2008). Community-based, consumer-directed services: Differential experiences of people with mild and severe intellectual disabilities. *Social Work Research, 32*(1), 55–64. http://dx.doi.org/10.1093/swr/32.1.55

Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism or Down syndrome: Effects on adult lives. *Journal of Intellectual Disability Research, 51*(9), 682–696. http://dx.doi.org/10.1111/j.1365-2788.2007.00954.x

O'Toole, C. J. (2013). Disclosing our relationships to disabilities: An invitation for disability studies scholars. *Disability Studies Quarterly, 33*(2), 5. http://dx.doi.org/10.18061/dsq.v33i2.3708

Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Research and Training Center on Community Living. (2013). *Residential services for persons*

with intellectual or developmental disabilities: Status and trends through 2011. Retrieved from http://rtc.unm.edu/risp11

Seidman, I. (2006). *Interviewing as qualitative research, a guide for researchers in education and the social sciences* (3rd ed). New York, NY: Teachers College Press.

Shogren, K.A., & Wehmeyer, M. L. (2015). A framework for research and intervention design in supported decision making. *Inclusion, 3*(1), 17–23. http://dx.doi.org/10.1352/2326-6988-3.1.17

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Forber-Pratt, A., Little, T., & Lopez, S. (2015). Casual agency theory: Reconceptualizing a functional model of self-determination. *Education and Training in Autism and Developmental Disabilities, 50*(3), 251–263.

Taylor, S. J., & Bogdan, R. (1998). *Introduction to qualitative research methods: A guidebook and resources* (3rd ed.) New York, NY: John Wiley & Sons.

Taylor, J. L., Burke, M. M., Smith, L. E., & Hartley, S. L. (2016). Families of adolescents and adults with intellectual and developmental disabilities. *International Review of Research in Developmental Disabilities, 50,* 195–231. http://dx.doi.org/10.1016/bs.irrdd.2016.04.001

Tesch, R. (1990). *Qualitative research: Analysis types and software tools.* New York, NY: Falmer.

Wood, W. M., Fowler, C. H., Uphold, N., & Test, D. W. (2005). A review of self-determination interventions with individuals with severe disabilities. *Research and Practice for Persons with Severe Disabilities, 30*(3), 121–146. http://dx.doi.org/10.2511/rpsd.30.3.121

Authors:

Meghan M. Burke and **Chung eun Lee,** University of Illinois at Urbana-Champaign; **Sarah A. Hall,** Ashland University; and **Zach Rossetti,** Boston University.

Correspondence concerning this article should be addressed to Meghan M. Burke, University of Illinois at Urbana-Champaign, Dept. of Special Education; 1310 S. 6th Street, Champaign, IL 61820 (e-mail: meghanbm@illinois.edu).