# Intellectual and Developmental Disabilities

## Self-Advocate and Family Member Experiences with Supported Decision Making
### --Manuscript Draft--

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Supported decision making (SDM) is a needed focus of policy and practice to enhance opportunities for people with disabilities to exercise self-determination as they are supported to make decisions about their life. This study used content analysis to analyze five focus groups comprised of 27 adults with IDD and 16 family members to understand how people with IDD use supports for decision making and how families support decision making. People with IDD and family members described a range of strategies and supports they used for decision making, including engaging trusted supporters, accessing technology, and using early experiences to build decision making skills. Findings from this research can inform development of practices and policy to enhance use of SDM in research, policy, and practice.

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# Abstract

Supported decision making (SDM) is a needed focus of policy and practice to enhance opportunities for people with disabilities to exercise self-determination as they are supported to make decisions about their life. This study used content analysis to analyze five focus groups comprised of 27 adults with IDD and 16 family members to understand how people with IDD use supports for decision making and how families support decision making. People with IDD and family members described a range of strategies and supports they used for decision making, including engaging trusted supporters, accessing technology, and using early experiences to build decision making skills. Findings from this research can inform development of practices and policy to enhance use of SDM in research, policy, and practice.

Years of research on self-determination has demonstrated that when people have increased opportunities to make decisions in their life, they experience better quality of life, employment, and community living outcomes (Lachapelle et al., 2005; Nota et al., 2007; Shogren et al., 2015). Making decisions is an important way to exercise self-determination, yet, adults with IDD frequently have fewer opportunities to making decisions for themselves throughout their lives (Khemka & Hickson, 2021). Supported decision making (SDM) provides a framework to enhance opportunities for people with IDD to exercise self-determination as they are supported to make decisions about their life. The United Nations' Convention on the Rights of Persons with Disabilities (2006) defines SDM, as "the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal and legal matters." SDM is an individualized process that will look different for every person. Supports needed for decision-making can and will change over time and across decisions based on the person's decision making experiences and the environmental demands for each decision, including the risk and complexity and risk of each decision (Shogren et al., 2017).

SDM has increasingly been recognized as a legal alternative to restrictive, plenary guardianship arrangements for adults with IDD (Martinis, et al., 2021). Under guardianship arrangements people with IDD, by definition, lose legal agency for decision making, which limits opportunities to develop self-determination through adulthood (Shogren et al., 2019). However, the estimated number of adults ordered into guardianship has tripled in recent decades (Shogren et al., 2021; Uekert & Van Duizend, 2011), and youth aged 18 to 22 with intellectual or developmental disabilities are most likely to be under guardianship arrangements (Bradley, et al., 2019). The use of SDM, particularly as an alternative to guardianship, can have lasting impact on people's everyday lives. For example, people not under guardianship arrangements are more

likely to live in their own home; work in competitive, integrated employment; and have their rights respected (Bradley, et al., 2019).

While researchers and policy makers have argued that SDM can be used as an alternative to guardianship, little is known about how SDM is practiced in the day-to-day life of people with IDD and their families. Shogren and Wehmeyer (2015) developed a framework for understanding supported decision making in policy and in practice, identifying three key areas to consider: the person's decision-making abilities, the opportunities for decision making, and needed supports for decision making. Supports in this framework are defined as "resources and strategies that aim to promote the development, education, interests, and personal well-being of an individual and that enhance human functioning" (Schalock et al., 2010, p. 175). Also, supports could include assistance from another person, technology (e.g., reminders or a map on a smartphone), or education and training (Shogren et al., 2018). Understanding the supports needed to make a particular decision involves evaluating (1) the person's experience and ability to make a particular decision; (2) the context, in terms of the risk and complexity of the decision, and (3) the supports needed to make and enact the decision (Shogren et al., 2017).

As the focus on developing legal and practice frameworks that enable supported decision making continues to grow, there is a need to understand (1) how people with IDD use SDM in their daily life and (2) how family members support decision making. Such information could serve the dual purpose of informing practice-based strategies that can be used by people with IDD and their families as well as identifying approaches to SDM (e.g., legal, organizational, planning) that need to be further researched and developed. Therefore, the goal of this study was to learn from people with IDD and their families about how they use supports to make decisions. Our study was guided by the following research questions:

1. How do people with IDD use supported decision making?

2. How do family members support their family member with IDD in using supported decision making?

3. What types of supports are used by people with IDD and their families to make decisions across different contexts?

**Method**

Five focus groups were conducted between December 2019 and April 2020 with adults with IDD (hereafter referred to as "self-advocates") and family members of a person with IDD. Three of the five focus groups were conducted only with self-advocates (two were in person before the COVID-19 pandemic, and one was conducted remotely via Zoom during the COVID-19 pandemic). The other two focus groups were conducted only with family members (one was in-person before the pandemic, and the other was conducted remotely during the pandemic).

**Focus Group Participants**

After receiving Institutional Review Board (IRB) approval, participants were recruited in one Midwestern state by sharing recruitment materials through local and state disability organizations' (e.g., Developmental Disabilities Council, state and local self-advocacy groups) email listservs and social media platforms. Inclusion criteria for self-advocates included (a) 18 years of age or older and (b) self-reported intellectual and/or developmental disability, and (c) had experience using supports to make decisions. Inclusion criteria for the family participants were (a) 18 years of age or over and (b) self-reporting having a family member of any age with IDD, and (c) had experience supporting the decision making of their family member with an intellectual and/or developmental disability. Since the purpose of the study was not to examine how the specific pairs of self-advocates and their family members were using the SDM, family

member participants were recruited separately from self-advocates, and we did not ask if family members or self-advocates were related to other participants. Participants provided informed consent, including a plain-language consent form for self-advocates. If self-advocates had a legal guardian, the self-advocate provided assent, and the legal guardian provided informed consent.

A total of 41 participants (27 self-advocates and 16 family members) participated. Tables 1 and 2 provide demographic characteristics of the self-advocate (Table 1) and family member (Table 2) participants. They resided in rural or suburban areas of one Midwestern state. This state was chosen because advocates in the state had been educating families and people with disabilities about SDM in support of legislation that was being discussed in the State Legislature that would formally recognize SDM as an alternative to guardianship. The majority of self-advocates identified as female (63%), and the age range was 22 to 70 years old, with a mean age of 41.19 (SD=12.19). Most self-advocates identified as European American/White (n = 25; 92.6%) and did not have a legal guardian (n = 20; 74.1%). About half were living on their own in the community, while the other half were living with two or more roommates. For the family member focus groups, the majority of participants identified as female (68.8%). Ages of family member participants ranged from 29 to 63 years old, with a mean age of 50.2 (SD=10.41). Twenty five percent (n=4) of family member participants reported supporting family members with IDD under the age of 18. Similar to the self-advocate sample, most of the family members identified as European American/White (14; 87.5%). Ten (63%) family member participants reported being guardian of their family member with IDD.

**Focus Group Procedures**

Focus groups were conducted by research team members who had lived experience relevant to the experiences of the participants in the focus group (e.g., a self-advocate who used

SDM conducted the self-advocate focus groups, and a family member who supported their child with a disability to use SDM conducted the family member focus groups). Separate focus group questions were developed for self-advocates and family members. Members of the research team with lived experience first drafted the questions for the focus groups, and the entire research team reviewed and provided input on the questions and aligned them across the self-advocate and family focus groups. For example, one of the questions for self-advocates was "What is an example of a decision you made recently?" Then, self-advocates were asked "Who or what supported you to make these decisions?" One of the focus group questions for families was "What supports do you have in place to help your family member make decisions?" Our interest was on understanding daily practices with supporting decision making rather than focusing on formal processes (e.g., guardianship). Therefore, we did not initially ask about formal processes that were in place. Family members, however, did discuss guardianship as a support that was used, so we explored guardianship with family members. Self-advocates did not mention guardianship as a support for decision making, therefore we did not explore guardianship with self-advocates.

The length of the focus groups ranged between 45 minutes and 90 minutes, and either audio recorded on a password-protected digital tablet for in-person focus groups or video recorded on a password-protected computer for Zoom focus groups. Then, these recordings were transferred to a HIPAA-compliant server, erased from the tablet, and sent to a third-party transcription company that produced de-identified transcripts. Two researchers checked for any transcription errors by comparing transcripts to the original audio recording, and when they found such errors, they corrected them based on what was in the original audio recordings.

**Analysis**

We used a content analysis approach to analyze focus group data (Hsieh & Shannon, 2005), and also throughout the data analysis process, people with lived experience were embedded. In the content analysis, the focus is on identifying codes that emerge from the data that are then grouped into broader themes. An emergent approach is appropriate given the limited research on how people with IDD use SDM. Transcripts from self-advocate and family focus groups were analyzed simultaneously so that researchers could understand decision making approaches and supports from multiple perspectives, although themes were organized. Initial codes were identified by two coders who did not conduct focus groups, who independently read all the transcripts. Microsoft Excel was used to organize codes for rating. One of the coders had lived experience as a sibling of an adult with intellectual disability. Once each coder generated initial codes, the two coders and the lead researcher (first author of this manuscript), who was present at all focus groups, came together and created a codebook. They further discussed emerging themes based on the codebook until there was agreement and collaboratively refined the themes and generated theme definitions. The themes and definitions were then further refined based feedback from team members who conducted the interviews, one of whom had lived experience as a self-advocate who uses SDM, and the other who had lived experience as a family member who supported decision making. Once the themes and codebook were finalized, the original coders re-coded the transcripts using the themes.

**Results**

Self-advocate and family member participants shared diverse experiences with supported decision making. Two main themes, decision-making supports and creating opportunities for decision-making, were reflected in both the self-advocate and family focus groups. While there was some overlap, there were also distinct perspectives reflected in the self-advocate and family

perspectives. In the following section, rich descriptions of the three themes, using quotes from the participants are organized by self-advocates and family members separately. This is because a third theme: difficult decisions about guardianship only emerged in the family focus groups. Additionally, to authentically capture the participants' voices, we did not make edits to their verbal statements or wording.

**Decision-Making Supports**

Overall, family members and self-advocates identified different supports for decision making, with self-advocates focusing on trusted supporters (e.g., family members, friends, professionals, and paid supporters), while family members saw themselves as the primary supporters and used technology and other forms of support to supplement their own support.

*Self-Advocates' Perspectives*

When asked about the supports used for decision making, self-advocates mainly described other people, particularly family members and paid support providers (e.g., case managers, direct support professionals) who they trusted to support their decision making. Using these trusted supporters, self-advocates described their process for determining which supporters to solicit advice for different types of decisions. For example, one participant who lived on his own but received case management services from a Home and Community Based Services (HCBS) waiver-funded provider described how he navigated supports for relationships: "I talk to friends if it [the decision] involves family. If it's relationship dating wise, I worry about it on my own. And if it's just that there's this thing with friends, I talked to IL [independent living counselor]." Another self-advocate who did not receive services or supports from a provider noted the importance of natural supports (e.g., people who are not paid to provide supports) as "that's one thing, when you don't get services, relying on natural support is a big thing." Another

self-advocate, highlighting the important role of family members, explained that her partner and daughter helped her navigate medical appointments, medication management, and conversations with health care providers. She said, "Normally, if my husband can't go with me, I bring my daughter because I don't understand half of the stuff. I have to explain to them [medical professionals], 'It's because I don't understand what you're saying. You're talking doctor terms." This participant also shared an instance when a health care provider did not believe her when she explained that a newly prescribed medication was not working for her. Through this experience, she emphasized the importance of family support as well as her own advocacy to obtain a needed medication change.

In other instances, family members suggested useful supports. One self-advocate talked about a suggestion made by their brother: "My brother told me many years ago to write everything down in a book, so if goes wrong, I have everything written down." This self-advocate recognized taking notes as one of essential daily supports for decision making. These experiences from self-advocates illustrate the importance of having and utilizing social networks to support decision making. Although this was the only example of non-person support mentioned by self-advocates, family members discussed non-person support more in depth.

### Family Members' Perspectives

Family members described themselves as key supporters for their family member with IDD. The majority of family members described specific ways they supported their family members with IDD to gain experience with decision making. For example, one parent described their method for supporting their child to think through the options and outcomes for health-related decisions as "we break it [information from the doctor] down and make sure she totally understands the ramifications of what the doctor said and why she should do it." Similarly,

another family member noted the importance of using plain language: "I basically summarize to my son what I understood the doctor to say and try to put it in ways he will understand and in front of the doctor and look to the doctor and say 'Is that correct?'"

While seeing themselves as key supporters, family members also described other types of supports that their family member with IDD used or were learning to use as decisional supports. For example, one family member described how digital devices supported communication with their 14-year-old son and also emphasized the importance of brainstorming problem-solving steps if such devices did not work as expected. For financial decisions, one parent described their son's use of online banking: "Since he can use his phone so well, he can check [online banking] … He's been spending capriciously for quite a while, but at least he'll experience what happens when your balance says two dollars and you can't use the card." This story exemplifies how decisional support can be used to understand consequences and reflect on choices made and the impact on outcomes. Some family members also highlighted the need for more formal types of supports, such as special needs trusts and ABLE accounts to support financial decision making.

Not all families identified ways they created opportunities and supports for decision making, however. Some family members indicated that they made the majority of decisions for their family member with IDD. For example, one family member stated "I have a 38-year-old daughter with cerebral palsy and a learning disability, so most of the major decisions are made by us, her parents." Another family member noted "My son is 35, and basically I make all the decisions for him… He has an idea of what he needs, but he doesn't know the process to go through it to get it … but he hasn't expressed a desire to want to take care of that business himself." This family member attended the focus group with his adult daughter without disabilities, who approached supporting her brother to make decisions differently. Specifically,

the daughter described ways that she would involve her brother in decision-making for every-day decisions, such as when and why to take medications: "With my brother, part of what we do is we talk about his medications… I would ask 'Hey, brother, what do you feel when you're on this one [medication]? Did you prefer when you were on that other one? Are you okay with these benefits and these cons?' We would just talk it out."

**Creating Opportunities for Decision Making**

Overall, self-advocates identified self-advocacy and goal setting as ways to create opportunities for decision making. Although family members used various ways to create decision-making opportunities, there was variability in the degree to which family members felt that a range of support opportunities and experiences was important.

*Self-Advocates' Perspectives*

Self-advocates described how their goals changed over time as they moved through different life stages, and this created new and different opportunities for making decisions. Self-advocates described a variety of reasons and ways that they recruited supports for their decisions. For example, one self-advocate, when describing their decision around living a healthy lifestyle noted that "I have a pillbox and I fill it with my own medication. I have IL [independent living counselor] come in and check my pillbox." Another self-advocate emphasized that they made all the decisions about money such as how much to spend on a daily basis "unless I do big stuff like purchasing a television and cars." Another self-advocate, describing the importance of saving money said, "What I saved my money for was my tattoo. It took me a while because I needed to save have a whole bunch of money." Related to employment, one self-advocate described retirement as an opportunity to find another job: "I retired out of one job, and I said, 'Hey, I want a change.' I choose to work at [a day care for children]. I applied and I got the job."

*Family Members' Perspectives*

Families generally described three approaches for creating opportunities for decision making: (1) establishing family routines that support involvement in family decisions, (2) engaging the family member with IDD in decision making from a young age, and (3) modeling expectations and supports for decision making in the way you might for children without disabilities. Below, we will describe these subthemes.

**Establishing Family Routines.** Many family members described opportunities they have built into family decision making to support the family member with IDD to develop abilities and experiences with decision making. One family member remarked that "we probably don't make a single decision without me asking for his [an adult with intellectual and developmental disability] input." Further, another family member described the long journey to finally find a doctor's office which values the input from their adult son: "We went through clinics where the receptionist wasn't receptive to even having a conversation in his way…. we had to find someone he feels safe in the waiting room and then where he knows the people there let him make choices." This family member also elaborated on how they asked their adult son for permission to disclose his disability to provide him with opportunities to make decisions.

**Engaging in Decision Making from a Young Age.** Other family members with young adults with intellectual disability pointed out the necessity of starting early in life to support their family member to make decisions. For example, one parent of a female youth with significant medical support needs explained how they were providing opportunities for her to make medical appointments, renew prescriptions, and discuss health issues and healthy habits directly with physicians "to help her understand that every day the decisions that she makes besides making

the appointments and her medications is her lifestyle." They viewed this as essential to support

engagement and decision making about health supports over the life course.

**Using Siblings as Models for Expectations and Supports.** Parents who also had

children without a disability described how siblings without a disability have been involved in

shaping opportunities and supports for their sibling with a disability's decision making, both as

points of reference for parents and as role models for their sibling with a disability. For example,

one parent described how she evaluated the level of support she provided for her adult child with

disabilities by comparing the degree she would support her adult child without disabilities:

> What I started to do with my daughter is to think about how I treat my 21-year-old son
>
> who is in college and still dependent to some degree and really try to augment how I
>
> address him and his needs and give her what she needs but then try to parallel the two.
>
> That has been helpful for me. Obviously, there's a balance and there's a give and take,
>
> but I'll start to say 'Would I say that to my son? No, I wouldn't.' That has been a big
>
> epiphany for me to back away.

Another parent noted that siblings can model and encourage decision making for their

sibling with a disability, including modeling that everyone uses supported decision making:

> I think one of the most powerful tools we have is the siblings. We have to do this SDM
>
> with all of our family members. One, he's [their son without IDD] closer in age and he
>
> knows what's age appropriate. Two, he's going to be there when we're not.

While many family members described how they created opportunities for their adult

child with a disability to make decisions, not all family members felt this was important. For

example, one parent who stated the family made the major decisions for their 38-year-old

daughter with cerebral palsy and a learning disability said, "She does have problems if you give

her too many choices … we let her pick just some daily stuff, like picking clothes, what she would want to have for supper. Just very minor decisions." Another parent talked about giving gift cards as a means to provide financial support to their 32-year-old son with IDD because the son had not been taught to use a credit card and frequently spent more than budgeted.

**Difficult Decisions about Guardianship**

Decisions about guardianship and decision making about guardianship only occurred in family member focus groups. Family members described the complicated decision-making process related to whether or not to obtain guardianship for their family member with IDD. Overall, four subthemes were emerged: (1) A difficult balance between protecting the family member's safety and promoting self-determination, (2) systematic barriers to SDM as an alternative to guardianship, (3) power of attorney as an alternative to guardianship, and (4) needed information about guardianship and its alternatives.

*A Difficult Balance between Protection and Self-Determination*

Families articulated their internal conflict regarding guardianship as trying to strike a balance between protection and self-determination. One family noted "that fear, that mom protection of 'I want to protect her' versus 'I know I'm not going to be around forever and I need her to be independent and I need her to have her supports." Although this family member thought of pursuing guardianship around the time when their daughter with IDD was graduating from high school, the family member said, "I'm glad I didn't do the guardianship." The family member explained that the daughter had continued to develop self-advocacy skills and gained employment, an independent living arrangement, and a driver's license in her 20s. Another family described their decision not to pursue guardianship based on their family values:

My daughter's 17. For most of her life, I was going to do guardianship. Even talked to a

lawyer a few years ago about it. Had it all planned, and then I started to have second

thoughts about it. Then somebody told me 'Well, they can't vote.' I thought 'Wow to

take that.' We're a very politically active family. I am taking that away from my

daughter, the right to vote when we talk about politics all the time and yet I'm saying

'You're not allowed to do that.' It really started to make me rethink the whole process.

This family member went on to describe how she noticed her daughter enhancing her decision-making abilities and how that also influenced the family's decision on guardianship. The mother

observed "She has changed as well. So, maybe it's looking at it in a different way. Now, we will

not be doing guardianship." Similarly, another family member who did not purse guardianship

described their family's struggle with the decision as "I will say it comes from a place of fear ....

I want her to be independent, but I want to protect her … It's scary, and we're just going to have

to hope for the best and keep her safe."

***Systematic Barriers to Supported Decision Making as an Alternative to Guardianship***

On the contrary, there were family members who brought up the systematic factors that

compelled them to choose guardianship. For example, one family member shared how they came

to decide to pursue guardianship over their son with IDD because of the need for insurance and

the negative consequences.

It was the hardest decision I think I've ever made is to have somebody label him as

incapacitated. It was devastating … Part of our decision [to pursue guardianship] was that

for him to remain on our military insurance we had to have him declared an incapacitated

adult. Every four years, we have to go through the process again. I remember reading the

letter that was written, and I was reading out loud to my husband. In that moment you

forget your kid's sitting in the room. I look over, and [their son] was devastated. He was

crying. We don't say these things around him. We don't talk about him in that medical

way. We don't talk about what things he can't do. We talk about how he can do it …

That's why we really work hard to help him make his own decisions.

Another parent also shared a fear of medical and other emergency systems not respecting

her 27-year-old daughter's decisions, particularly in an emergency or while traveling. The parent

described how she wanted her daughter to be her own guardian like her siblings, but that she

feared as they traveled for disability advocacy work across the states and countries that in an

emergency she would not be able to advocate for or protect her daughter without guardianship.

### Power of Attorney as an Alternative to Guardianship

Other families chose to pursue a power of attorney instead of guardianship. One family

member described the experience when the family member and the son visited a lawyer's office

to proceed with a power of attorney:

When we were sitting in the lawyer's office, he seemed a little bit weary of that. I said

'Well, look. You're going to be making your own decisions but I can back you up or I can

help with the decision. For the most part, all of this will be for you to decide, I'll just be a

backup.' He was fine with that.

Another parent who has a 28-year-old son with IDD used of a power of attorney to

support their son's financial decisions but not medical decisions. They described their reasoning

as "he doesn't take any meds or anything … when it comes to medical decisions, … He is

starting to go to the doctors more and have time alone with the doctor so that he can make those

decisions." Another family member described a discussion when their son with IDD turned 18

and how they planned to rely on siblings for decision-making supports.

I explained to him about guardianship and that I really wanted him to be able to vote … I

said 'I want to give you every opportunity to be a whole person, the person you are' …

but I do have medical and financial power of attorney … I really like the guided self-

determination for him and his situation. Hopefully that won't change in the future.

*Needed Information about Guardianship and its Alternatives*

Finally, some families highlighted the need for more information about alternatives to

guardianship. Families indicated that other family members who have a child with disabilities

were the main source of information, and sometimes received incorrect information from

professionals (e.g., needing guardianship to communicate with school when a child reaches the

age of majority). Specifically, families discussed that in conversations with their child's school

regarding the age of majority, guardianship was the only option provided to support decision

making. One family member described their experiences with their transition coordinator:

In high school, we had a transition coordinator we met with about [our daughter's] goals

and those types of things, and that's who told us, that when she turned 18, that she should

have a guardian because obviously she is not able to make decisions for her own, so

that's what we did.

One family member, who recently learned about alternatives to guardianship from other family

members of a child with disabilities, summed this need up as:

We probably don't need full guardianship over him [son with IDD]. I want him to be as

independent as he can. I just feel like I need to educate myself more and make sure

whatever decision we make together, that it works for all of us."

**Discussion**

The purpose of this study was to understand the experiences of self-advocates using supports for decision making as well as the supports provided by family members. Findings from this study provide important insight into the types of supports self-advocates use for decisions and opportunities that were available for self-advocates. Family members described how and when they provided supports for their family member with IDD to engage in decision-making opportunities. Families also described factors that influence their decision making about guardianship and its alternatives. In this section, we will discuss implications of each key theme.

## Decision-Making Supports

### Self-Advocates' Networks of Supporters

Self-advocates, when asked about supports for decision making, primarily described how other people supported their decision making. It was clear from the self-advocates who participated in the study that they knew specific people they could turn to for support with decisions, and that this was important in their day to day lives. While self-advocates did describe how different people were able to provide supports for different types of decisions, most self-advocates identified family members or paid support staff as the people delivering those supports. This may be because people with IDD tended to have fewer people in their social networks and limited access to opportunities for expanding their social networks. This finding is consistent with previous research on the social networks of people with IDD which has found that people with IDD tended to include more professionals in their social networks than people without disabilities (van Asselt-Goverts et al., 2015). This suggests the criticality of additional research on ways to build and expand social networks to enhance supports for decision making.

Robust and diverse social networks have the potential to afford people with IDD the opportunity to use different supporters for different types of decisions (e.g., a person may reach

out to co-workers rather than paid support providers when making decisions about employment), which could be enhanced through participation in inclusive postsecondary education and integrated community employment (Prohn et al., 2019). More research is needed on how self-advocates build their social networks. Self-advocates have written about this process (Hatch, 2015; Linnenkamp & Dean, 2019). For example, Linnenkamp, in Linnenkamp & Dean (2019) noted

> One thing that I think is cool is that [my main supporter] is helping me make day-to-day decisions and then I have other supporters who are co-workers and friends who are there to bounce ideas off. All of those people help me with my decisions. I can bounce ideas off them and get their feedback, but I end up making the final decision for myself. (p. 32)

While more research is needed to understand the degree to which the size of social networks influences the supports available for decision making, this study and other literature suggest that more research is needed to expand social networks, building on the lived experiences of people with IDD who have undertaken this work in their lives.

Relatedly, family members in this study, including siblings, discussed the importance of siblings in the lives of their siblings with IDD. As supported decision making touches on all aspects of one's life, there is a need to further explore the informal and formal role that siblings play as supporters for their siblings with IDD's decision making, including any educational resources and ongoing supports that siblings may need to serve as decision-making supporters aligned with their family and cultural contexts (Burke et al., 2022).

### *Use of Technology as Key Supports for Decision Making*

In addition to people acting as supporters, families also highlighted how technological supports such as communication devices or online tools, such as online banking apps, could be

used to support decision making for their family member with IDD. Interestingly, self-advocates did not highlight technological supports. While many of the self-advocates used smartphones for communication and accessing information online, it may be that people with IDD are so used to supports being described as people that they did not think of other forms of support. Or this could have been because using a smartphone or other technologies is so ubiquitous people with IDD did not think of this as a decisional support. However, as research also has shown that people with IDD primarily use technology for communication (Fisher et al., 2020), ongoing issues related to technology access and utilization (Pew Research Center, 2021) need to be addressed to enhance the available array of decisional supports.

While barriers for accessing technology exist for people with IDD, families in the study described technology as a way for the family member to maintain some level of control over decisions – especially related to financial management. This may have also contributed to how people with IDD viewed technology as a support, which should be explored in ongoing research. Exploring ways to shift how families perceive the role of technology in creating opportunities and empowering supported decision making may be an important area of ongoing development. For example, self-advocates' decision making may be enhanced from personal and family education and ongoing training for utilizing technology (Fisher et al., 2020), specifically to support financial and other critical domains of decision making. More research is needed on the benefits and drawbacks of technology in supporting decision making.

**Creating Opportunities**

*Culturally Sustaining Supported Decision-Making Opportunities*

This study highlights the importance of providing equitable decision-making opportunities and experiences with people with IDD. Also, findings from this study align with

previous research on self-determination suggesting that supporting people to develop skills and abilities related to self-determination (e.g., decision making) needs to start early in life, and that people benefit from their supporters holding high expectations and provide support for enhancing self-determination (Wehmeyer et al., 2017).

Findings also highlight the importance of creating autonomy-supportive environments where people have opportunities to make choices, and supporters listen to the person's perspective and support self-determination (Dean et al., 2021; Grolnick, 2009). Research on effective methods for supporting families to create autonomy-supportive environments is limited (Dean et al., 2021). However, research suggests that collaborating with families when implementing self-determination interventions (e.g., the Self-Determined Learning Model of Instruction; SDLMI) can be effective in enhancing self-determination for people with IDD, including decision making and problem solving (Hagiwara et al. 2019; Park & Kim, 2012).

Essential to such collaborations are recognizing and respecting both individual and family preferences and values, and infusing cultural humility into all practices to support self-determination and supported decision making. More research is needed in this area, with a focus on engaging the marginalized families and centering their experiences in the development of models and supports for decision making.

Ultimately, families are key supporters for people with IDD throughout the life course and implementing person-family-centered training in the context of the movement toward supported decision making as an alternative to guardianship is needed. A focus on culturally sustaining practices can be infused into this work (Hagiwara et a., in press). To enable this, more research is needed to understand the ways families, including those from marginalized cultural and linguistic backgrounds, support decision making for people with IDD and engage in familial

decision-making – and develop and test culturally sustaining supported decision-making approaches and strategies that honor their cultural and family backgrounds.

### *Interventions focused on Supported Decision Making*

Families in this study emphasized that they needed more information and more frameworks to understand supported decision making. Structured interventions have also been developed to create opportunities and supports for decision making, and more work is needed to research and disseminate these frameworks and understand how they can advance supported decision making. For example, Deciding My Future is an intervention that was developed in partnership with self-advocates with IDD which supports youth to critically evaluate decisions and plan for supports (Dean et al., 2020). Using this intervention, people are supported to work through four steps of a decision-making and support planning process based on a social-ecological model of decision making (Shogren et al., 2021).  Interventions such as Deciding My Future hold promise for supporting people with IDD to make decisions, plan for supports, and learn from their experiences. More research is needed on the efficacy of such interventions on enhancing the person's skills, knowledge, and abilities to engage in supported decision making, including how families can be engaged in this process and how systems of supports for decision making can be created and sustained.

### Difficult Decisions about Guardianship

The findings from our study also highlight how families perceived decision making around guardianship. Many families highlighted significant complexities and varying factors that influenced their decision making. Although not all families agreed on the appropriateness of guardianship for their family member, all reported wanting to empower their family member with IDD to make decisions in some situation. Families that did pursue guardianship highlighted

a range of beliefs about decision making abilities, contextual factors related to how systems (e.g., medical, financial) perceived their family with a disability, and family history as reasons why they decided to pursue guardianship. It should be noted, however, that consistent with SDM, best practice for guardians is to support the person to make and express their decisions before making decisions on the person's behalf (National Guardianship Association, 2022). Families that exercised SDM as an alternative to guardianship also highlighted specific beliefs and values, such as the importance of voting, as shaping their decision making.

Additionally, families expressed that they did not receive adequate information from school personnel when their family member approached the age of majority on guardianship and alternatives to guardianship. A recent review of school transfer of rights practices when students with intellectual and developmental disabilities reach the age of majority (18 in most states) found little empirical evidence regarding school practices (Landa et al., 2023). However, the existing data did suggest that families often first hear information about guardianship from school personnel who often have limited knowledge of guardianship, yet often recommend families seek guardianship (Landa et al., 2023; National Council on Disability, 2019). This suggests a need for research on effective training and supports for youth with disabilities, families, school professionals, and others on the range of legal options that are available and the implications of various options, particularly guardianship, to long term legal agency.

Families in our study that reported using SDM early in their child's life described that SDM became a part of family practices and values, and guardianship became less of a concern. This finding suggests a need for research and practice to focus on enhancing support for decision making across the lifespan and planning for information on SDM to be given to families early in their child's life. This can potentially enhance collaborative relationships and culturally

sustaining practices to promote self-determination and decision making across home and school environments, aligned with family values and cultural practices.

Families in this study did, however, highlight how systemic barriers to using SDM existed and play a role in their decision making. For example, if healthcare providers, financial institutions, or schools do not understand and honor SDM arrangements, it becomes difficult for family members to obtain the necessary information to effectively provide support for their child with IDD to make decisions. Further, if one state recognizes SDM arrangements as a legal alternative to guardianship while the family receives support or services in another state, a trusted supporter may have difficulty obtaining access to information regarding the supports and services. These examples highlight the need for systems change initiatives that break down systemic barriers and are proactively designed to recognize SDM arrangements and ensure trusted supporters have access to the information needed to support decision making.

**Limitations**

When interpretitng this research, several limitations that should be taken into consideration. First, the focus of this study was on people with IDD and familiy members who were familiar or used SDM; therefore, findings do not represent the experiences of people who do not use or recognize the use of SDM in their lives. Further, recruitment for the study was done entirely online, through social media and emails from disability-related organizations. Therefore, the sample may be biased toward people who have access to technology, use technology for communication, and are connected to disability-related organizations. In-person research restrictions due to the COIVD-19 pandemic also impacted recrutiment during this study, resulting in a smaller than expected sample size. More work is needed to understand experiences from a broader range of family members and self-advocates. Relatedly, the sample from this

study was drawn from one Midwestern state and the sample was largely White/European American. While many of the issues discussed by families and self-advocates may be shared by the broader disability community, there is a critical need to center the experiences of families that experience other forms of marginalization based on race and ethnicity so that policy and practice can elevate these needs in the generation of solutions regarding SDM and guardianship. Finally, efforts were not made in this study to link self-advocate and family member responses. It would be interesting to study SDM within a family context, exploring family member and self-advocate practices and perspectives together, however that was not a focus of this study. More work is needed to understand SDM from the family context.

## Conclusion

This study highlights the experiences of families and self-advocates who use SDM in their daily life. Findings from this study can be used to identify and develop practices that researchers, practitioners, policy makers and professionals can use to support people with IDD and their families to create opportunities for decision making. In particular, findings from this research suggest a need for increased focus on work that supports the expansion of social networks, technology to support decision making, and access to information and supports that advance supported decision making. For family members, in particular, practices are needed to support families in identifying ways to create opportunities for decision making early in life and develop family routines that embed opportunities for decision making within the family's daily life to lead to access to opportunities for decision making across the life course.

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Table 1

*Self-Advocates' Demographic Information*

| Variable | n | % |
|---|---|---|
| Gender | | |
| Male | 7 | 26 |
| Female | 17 | 63 |
| Other | 2 | 7.4 |
| Missing | 1 | 3.7 |
| Age Range | 22 – 70 | |
| Age Mean | 41.19 | (SD = 12.19) |
| Race/Ethnicity | | |
| European American/White | 25 | 92.6 |
| African American/Black | 1 | 3.7 |
| Latinx | 1 | 3.7 |
| Guardian Status | | |
| Having a guardian | 5 | 18.5 |
| Not having a guardian | 20 | 74.1 |
| Missing | 2 | 7.4 |
| Living Arrangement | | |
| With family | 1 | 3.7 |
| On their own home/apartment | 12 | 44.4 |
| With one roommate | 1 | 3.7 |
| With two or more roommates | 11 | 40.7 |
| Missing | 2 | 7.4 |
| Employment | | |
| Integrated employment | 9 | 33.3 |
| Sheltered work program | 16 | 59.3 |
| Missing | 2 | 7.4 |

| Who supports you the most when making decisions? | n |
|---|---|
| Parent | 14 |
| Sibling | 8 |
| Grandparent | 2 |
| Friend | 12 |
| Spouse | 3 |
| Other | 14 |
| Paid professionals | 11 (e.g. case manager, staff, nurse) |
| Bosses | 1 |
| Daughter | 1 |
| Myself | 1 |
| Missing | 1 |

Note: The percentage of gender and living arrangement do not add up to 100% due to a rounding issue. *Self-advocates were allowed to choose multiple supporters; therefore, it goes over 100%.

Table 2

*Families' Demographic Information*

| Variable | n | % |
|---|---|---|
| Gender | | |
|   Male | 4 | 25 |
|   Female | 11 | 68.8 |
|   Other | 1 | 6.3 |
| Age Range | 29 – 63 | |
| Age Mean | 50.2 | (SD = 10.41) |
|   Missing | 1 | |
| Race/Ethnicity | | |
|   European American/White | 14 | 87.5 |
|   Asian | 2 | 12.5 |
| Age of person with a disability family assists | | |
|   5-11 years old | 1 | 6.3 |
|   12-17 years old | 3 | 18.8 |
|   18-21 years old | 4 | 25 |
|   27 years old and over | 8 | 50 |
| Guardian Status | | |
|   Being a guardian | 10 | 62.5 |
|   Not being a guardian | 4 | 25 |
|   Not sure | 1 | 6.3 |
|   Missing | 1 | 6.3 |

*Note:* The percentage of age range of the oldest child and guardian status do add up to 100% due to a rounding issue.