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ORIGINAL ARTICLE

Instrumental Support: Accounts from Adults with Intellectual and Developmental Disabilities

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Abstract

This qualitative study used an inclusive and participatory research approach to examine the perspectives of people with intellectual and developmental disabilities (IDD) on instrumental supports. Instrumental supports include concrete and direct ways people assist others in solving a problem or accomplishing a task, including helping to access and navigate formal supports and services. Natural supporters play essential roles in setting up and maintaining formal supports for individuals with IDD. Family members that provide instrumental support are responsible for integrating the formal and informal supports for the best mix of supports based on the person with IDD's needs and preferences. This study examined the instrumental support people with IDD received from and gave to their families related to physical support, healthy living, financial support, and navigating formal services. Thirty virtual interviews were conducted using the dyadic interview method with 10 adults with IDD and 10 family members who they chose. Findings showed that people with IDD received natural supports from their family in numerous areas including physical help, support to be healthy, and financial support. Also, families helped with formal supports by navigating the system of services for people with IDD. In addition to receiving support from their families, people with IDD also provided some reciprocal support to their families, specifically in the areas of physical help and healthy living. Implications for practice and policy are shared along with directions for future research.

Keywords Family support · Instrumental support · Natural support · Formal services

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People with intellectual and developmental disabilities (IDD) rely on instrumental support to help them thrive. Instrumental support is defined as concrete and direct ways people assist others in solving a problem or accomplishing a task (Barrera, 1986), including giving material goods or services (Thoits, 2011). This can include helping someone physically with daily living tasks, support for a person to be healthy, helping to navigate services, and providing financial assistance (Chronister et al., 2021; Langford et al., 1997; Tardy, 1985; Thoits, 2011). Helping to access and navigate formal supports and services, defined as paid supports accessed through a provider (Nuri et al., 2024), is an important aspect of instrumental support. Unpaid family and friends, often referred to as informal or natural supporters, play essential roles in setting up and maintaining formal supports for individuals with IDD (Sanderson et al., 2020). Family members that provide instrumental support are responsible for integrating the formal and informal supports (Friedman, 2023), ideally in a way that provides a strong foundation for people with IDD to lead self-determined lives. Without the help of these informal caregivers, many people with IDD would not have the publicly and privately funded formal services that are essential to their well-being (Nuri et al., 2024). Because the family members provide instrumental supports that combine formal and informal supports, people with IDD benefit from these integrated supports, which expands their options and allows for the optimal mix of supports based on their needs and preferences (Reynolds et al., 2023).

Discussions of support for people with IDD have traditionally focused on formal supports that are paid through governmental or provider funding sources (Reynolds et al., 2023; Sanderson et al., 2020). However, formal services for people with IDD are limited. According to the National Residential Information Systems Project (RISP), only 21% of people with IDD in the US were known to or served by the state IDD agencies in 2019 (Larson et al., 2022). In a study of 405 caregivers of individuals with IDD across four states, caregivers reported the following as important formal supports, included federal health insurance (61.7%), monthly cash stipends (58.8%), and Medicaid waivers (47.4%) (Santos et al., 2023). Another study of 796 siblings of adults with IDD found that enrollment in formal services was a strong predictor of the adult with IDD receiving daytime activities, which was associated with those who had less unmet needs (Lounds-Taylor & Hodapp, 2012).

The limitations of the formal support system place a significant burden on the natural support networks, especially families of people with IDD (Friedman, 2023). For example, Lounds-Taylor and Hodapp (2012) found that a lack of daytime activities for the adult with IDD was correlated with negative outcomes for their adult siblings, including depressive symptoms, ill health, and less-than-optimal relationships. Yet, receiving supports solely from formal supports is not feasible. The formal support system will never be able to provide all the assistance adults with IDD need to live the lives they want. In addition to other ways of accessing formal supports (Nuri et al., 2024), most often people with disabilities accessed formal supports through the instrumental support they receive from family members who provide assistance to learn about, sign up for, and maintain access to publicly and privately funded services.

Natural or informal supports have been found to increase the quality of life for people with IDD in multiple areas including increasing health, self-determination, community integration, and more (Friedman, 2023). Family members are often the primary provider of natural supports (Sanderson et al., 2017) and they play a role in enhancing the self-determination of people with IDD (Hagiwara et al., 2022). Also, adults with IDD often rely on their family members to help make connections for social support, which most adults with IDD struggle to do on their own (Araten-Bergman & Bigby, 2022; Bigby, 2008). Even when people with IDD receive formal services, often they need help from their informal support networks, such as family and friends, to access the formal support system. Without these informal supporters, many people with disabilities would not have the formal supports that provide essential services for their lives. A combination of formal services with natural supports can often achieve the best outcomes for individuals with IDD (Reynolds et al., 2018).

The support needs of adults with IDD vary across the life course based on the type of disability, developmental trajectory, changing needs, and access and availability of services and supports (Esteban et al., 2021; Hole et al., 2013). This study uses life course theory to examine people with IDD within the context of their family as well as the larger sociohistorical contexts (Dilworth-Anderson et al., 2011; Graff et al., 2008; Parker Harris et al., 2012). Life course theory looks at the way a person changes over time, especially how early experiences influence later outcomes (Graff et al., 2008). From a Disability Studies perspective, a person does not "have" a disability, rather a person experiences a disability. The environment plays a significant role in shaping the experiences of people with disabilities (Putnam, 2002) and life course theory informs understanding of these experiences.

There are a small number of research studies that examine the reciprocity within relationships between individuals with IDD and their families and include the perspective of the individual with IDD (e.g. Kramer et al., 2013; Giesbers et al., 2020; Walmsley, 1996; Williams & Robinson, 2001). One study that did include the perspective of people with ID interviewed eight sibling pairs of people with and without ID and found reciprocity in the sibling relationship (Kramer et al., 2013). Another study examined 138 individuals with ID on views about their family and found that about 30% thought of their relationships with family members as reciprocal (Giesbers et al., 2020). Scott and Havercamp (2018) examined self-reports of 90 adults with ID and a proxy they chose and found that it is important to ask individuals with ID about their own thoughts and feelings on social support, which may be reported differently from proxies. While there is some literature on social supports from the perspective of family members (Chronister et al., 2021), the views of people with IDD themselves are limited in the literature, especially related to integrated supports that include both formal and informal supports (Burke et al., 2015; Heller & Arnold, 2010).

This study examined the perspectives of people with IDD about instrumental support to learn directly from them about what helps adults with IDD lead meaningful lives. This study looked at both the support people with IDD received from and gave to their families related to physical support, healthy living, financial support, and navigating formal services.

Methods

This study, part of a larger study, serves to fill a gap in current family support research by exploring the perspectives and experiences of adults with IDD on instrumental supports. Through qualitative in-depth dyadic virtual interviews, the following research questions were explored in the larger study that examined various types of support including emotional, companionship, instrumental and informational support:

1. What types of support do people with IDD receive from their families?
2. What types of support do people with IDD provide to their families?

In the current study, the same research questions were used specific to instrumental support. Question one seeks to explore the ways in which people with IDD get instrumental support from their family members. Question two seeks to explore the mutual reciprocity in the supportive family relationship related to instrumental support. Together, these questions aim to further advance our understanding of family support centralizing the voices of people with IDD about instrumental support.

Inclusive and Participatory Approach

We used an inclusive and participatory research approach that involved a Community Advisory Committee (CAC) comprised of five adults with IDD. CAC members provided input at various points throughout the research process, including the interview protocol, pilot testing, recruitment, and data analysis. Engaging individuals with lived experience had a beneficial impact on the study overall by having expert guidance to help make the study more accessible and meaningful for the people with IDD who participated in the study and for the results to be more applicable and useful for the IDD community (Buck et al., 2024).

We developed the CAC specifically for this study. The demographics of the CAC members included two women and three men, one African American and four White members who ranged in age from 28 to 75 years old. CAC members were all receiving residential services from the same DD provider organization, and all knew each other. The lead researcher had an established relationship of trust and professionalism with the provider organization where she often volunteered her time and attended community events at the organization. She had a friendship with three of the members from interacting with them at community events. Because all the CAC members were already familiar with the researcher, this was helpful for them to work together in a collaborative manner on the research study. We identified CAC members because they expressed interest in the role after learning about the study. CAC members were not provided financial incentives, though the first meeting was held in a restaurant and the researcher paid for dinner.

We established an environment of co-learning among the CAC members and the researcher. To help alleviate power dynamics that often occur between researchers and advisory committee members, numerous strategies were employed (Ivankova, 2015). First, the researcher engaged the CAC members at the start of the study, explained general research processes, and clarified the role of the CAC members to provide honest and open feedback throughout the study by sharing their thoughts and ideas based on their own lived experiences. Second, we shared the purpose of the study with all CAC members, and all expressed they felt the study was important to help people with IDD and their families. This buy-in strengthened engagement of the CAC throughout the research process since CAC members believed they were participating in something that mattered (Kelly et al., 2017). Third, we created a safe space where all ideas were welcome. The researcher assured the CAC members that anything they said would be okay and there was no wrong answer. The CAC members understood that their lived experience was valuable, and they were able to share any thoughts or ideas that came to mind without fear of judgement during the process. Fourth, the researcher was vigilant to notice power dynamics and was intentional about interacting in a way that fostered equity in meetings. For example, we reiterated that all ideas were accepted and thanked each person when they contributed. Also, we provided time and space for CAC members to think about an idea and share their thoughts as well as ask questions if they needed more information (Ivankova, 2015).

The CAC members met in a group and individually at various points in the study including: discussing the best methods for the research and population (first group discussion), getting input on the interview protocol topics and questions (second group discussion), sharing ways to effectively include people with IDD (also second group discussion), reviewing the interview guides and visual support (individually providing one-on-one feedback to researcher), providing insight into the recruitment strategies and helping with recruitment (third group discussion), providing feedback on the themes that emerged from the analysis (fourth group discussion), and providing guidance for dissemination of findings (fourth group discussion).

The engagement of the CAC was an important way for people with IDD to participate in various aspects of the research. The CAC member met in four group meetings throughout the research process and gave input and guidance at different points along the way. Several individual or smaller group meetings were held with one or two CAC members who either were not able to make the group meeting or wanted addition time to share their thoughts and ideas. Two CAC members provided a thorough review of the interview guide questions for people with IDD before it was pilot tested. CAC members individually reviewed the visual support and provided input one-on-one to the researcher about the images to help make improvements before it was finalized.

The researchers utilized strategies for inclusive engagement of adults with IDD with CAC members, drawing from Ahlers and colleagues (2020). First, numerous ways to contribute were provided including group meetings, individual meetings, phone conversations, and email correspondence. Second, during the orientation process CAC members discussed their preferred communication styles and methods. For example, one CAC member preferred to meet with the researcher individually instead of in the group setting. Another CAC member requested plain language materials during the meetings, including visuals that would help her focus on the content of the meeting. Third, we provided multiple opportunities for input. The researcher encouraged CAC members to share whatever thoughts or ideas they had related to the research during group or individual meetings as well as in between meetings by calling, texting, or emailing the researcher. Fourth, we shared plain language materials during meetings and included visual prompts for specific topics. During the meetings, we thoroughly explained all materials. The CAC provided valuable input that shaped the study and helped improve the quality of the research, especially ensuring the inclusion of people with IDD with a range of capabilities and ways of expressing themselves.

Participants

Participants included ten adults with IDD and ten family members they chose. Participants were eligible for the study if they were adults with IDD (18 years or older) who were living in Illinois with a family member and had at least one parent and sibling who provided support to them in some way. Illinois was selected for this study due to the researchers' connections and relationships in the state. Table 1 shows the demographics of adults with IDD. The ages of the participants with IDD ranged from 20 to 64 years. This was a younger sample with most people in their 20s and 30s. 80% of participants with IDD were male. 50% were White, 30% Hispanic, 10% South Asian, and one person identified as Hispanic and White. 60% of the participants with IDD had a guardian, specifically their parents. Participants with IDD were asked to choose a key support person that would also be interviewed, and all participants chose a family member. In terms of who they chose, half (50%) chose their mother, 30% chose their father, and 20% chose their sister. Most of the participants, or 80% lived with their parent(s) and 20% lived with a sibling, specifically their sister.

Recruitment

We recruited people with IDD for the study. CAC members provided ideas for ways to recruit through disability advocacy and provider organizations and helped with outreach to the people and networks which they were connected. A purposeful sam-

Table 1 Adults with IDD by demographic characteristics

Participant with IDD (pseudonym)	Age	Gender	Race/ Ethnicity	Living arrangement	Guardian status	Family member and age
Brian	32	Male	White	Parents	Parents	Father (61)
Nick	22	Male	White	Mom and 3 siblings	Mom	Mother (54)
Tina	28	Female	White/ Hispanic	Parents and uncle	Parents	Father (60)
Nelson	36	Male	White	Mom	Mom	Mother (66)
Judah	20	Male	White	Parents and brother	Parents	Mother (49)
Peter	45	Male	South Asian	Sister, brother-in-law, 3 nieces and nephews, and dad	Self	Sister (47)
Sam	23	Male	Hispanic	Mom and brother	Self	Mother (50)
Erin	42	Female	White	Parents	Self	Mother (71)
Joey	64	Male	Hispanic	Sister	Self	Sister (69)
Ethan	40	Male	Hispanic	Parents	Parents	Father (73)

pling strategy was used for this study because specific people were intentionally sought for this study due to their knowledge and experience related to the perspective of people with IDD about family support who can provide rich information on this topic (Patton, 2015). Also, we used snowball sampling where people who participated were asked if they knew other people who may be interested in participating. Previous participants shared the opportunity with people they knew, resulting in the recruitment of two new participants. We recruited participants both broadly through social media and online forums, as well as targeted specific individuals through key contacts. For example, some organizations shared information with their networks through their newsletters, websites, and social media (i.e., Illinois Self-Advocacy Alliance, The Arc of Illinois) and key contacts at these organizations also sent a few emails to specific families they felt may be interested in the study.

Procedures

Data Collection

The university Institutional Review Board ensured the protection of human subjects and approved the research study. We collected data from participants after obtaining informed consent or assent from each of them. Then, we conducted virtual dyadic interviews using the semi-structured interview guides. Dyadic interviews provided an effective way to capture information about a specific topic from two people who have a relationship. Dyadic interviews provided a space for people with IDD to express themselves by sharing their personal thoughts and perspectives on family support, while also having them choose the key support person they wanted us to interview (Caldwell, 2014). In total, 30 individual interviews were conducted: 20 interviews with ten adults with IDD and ten interviews with a key support person who they chose. For the adult with IDD, each interview lasted between 10 and 44 min. For the key support person, each interview took between 43 and 65 min. All ten participant with IDD received a twenty dollar electronic gift card at the store or restaurant of their choice for their participation in the study. The family members did not receive anything.

For each dyad, a series of three interviews were conducted one by one (see Fig. 1). First, we interviewed the person with IDD, next we interviewed their family member, finally we conducted a second interview with the person with IDD. Interviews with adults with IDD lasted between 10 and 44 min and interviews with family members took between 43 and 65 min. During the first interview with the person with IDD, the researcher learned more about the communication style of the participant that was helpful in the second interview with that individual. Also, the interview with the family members provided contextual information about the participant with IDD that was helpful for the second interview with that person. In this way, the researcher was able to use more specific and targeted probes in the second interview with the participant with IDD to help gather relevant information for the study.

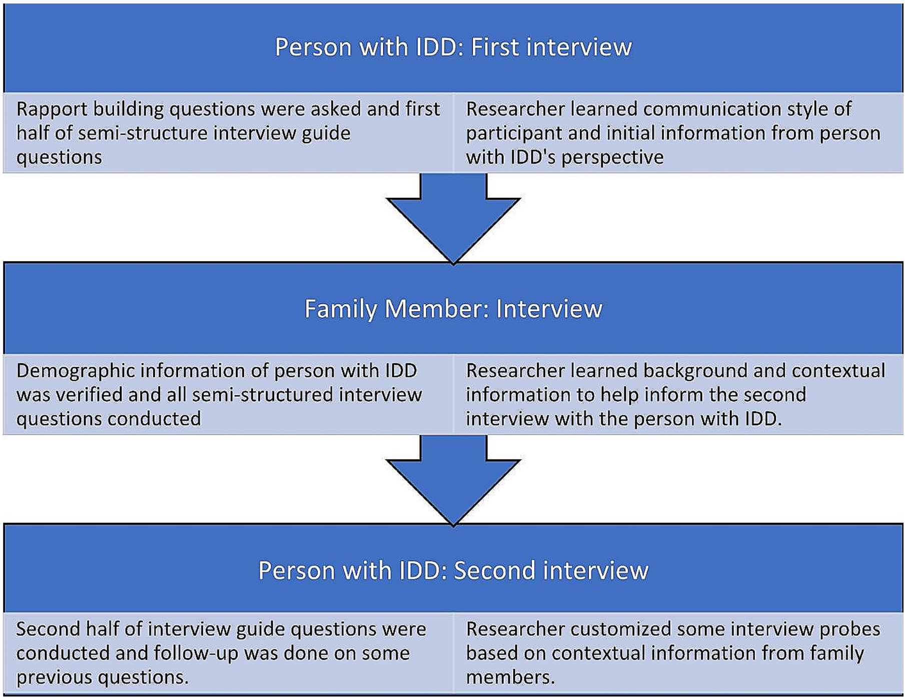

Fig. 1 Dyadic interviews with people with IDD and family members

Interview Protocol

We developed semi-structured interview protocols for the participants with IDD and their family members. The protocols were based on the social support literature (Langford et al., 1997; Uchino, 2004; Williams et al., 2004; Zhou, 2014), including social support research instruments such as the Social Support Behaviors Scale (SS-B) (Vaux et al., 1987), Interpersonal Support Evaluation List (Cohen & Hoverman, 1983), Waisman Activities of Daily Living Scale (Maenner et al., 2013), Social Support Self Report (SSR) (Lunsky, 1999), Reciprocity Measure (Horwitz et al., 1996), Child and Adolescent Social Support Scale (CASSS) (Malecki & Demaray, 2002), and Scale of Social Support (Barrera et al., 1981). Before finalizing the guides, the CAC members offered their input. The semi-structured interview guides included nine core questions (see Appendix A). These questions served as a starting point for common questions across the participants while also allowing flexibility for the interviewer to probe further on certain topics that came out (Patton, 2015). The family members were asked the same questions, just about the person with IDD. For example, we replaced the word "you" with the person with IDD's name. Before the protocols were refined and finalized, pilot testing was conducted with four people, including two people with IDD and two family members.

Researcher Identity

The primary researcher is a family member of people with IDD, specifically the mother of a child with developmental disabilities, and the sister of an adult with intellectual and developmental disabilities. This identity helped establish rapport with key contacts, gatekeepers, community advisory committee members and research participants. An essential element for conducting qualitative research is building rapport (Patton, 2015). Rapport was established by developing a genuine relationship with a person, being relatable as well as relating to that person, and creating a comfortable atmosphere so the person feels good about his or her participation in the research and contribution overall (Dion Larivière et al., 2023).

Data Analysis

We analyzed the data to determine the areas of support people with IDD received from and gave to their families. Throughout the analysis, we used a life course lens and took into consideration the ways people change over time, based on their past experiences (Parker Harris et al., 2012). We used a reflexive process of thematic analysis (Braun & Clarke, 2006) to conduct analysis of this study which was anchored to the research questions. We transcribed each interview verbatim and then coded. ATLAS.ti 9 was used to organize and code data during the analysis. First, we reviewed our field notes and transcripts to gain an overall sense of the data and then we generated initial codes. Second, we scrutinized each transcript in more detail and new codes were added to the codebook and current codes were refined. Third, we assessed the codebook from a broader perspective within the full scope of the data. Then, we used the codebook to sort and refine codes and begin developing themes. Fourth, we re-coded the transcripts with the updated version of the codebook. CAC members reviewed and discussed preliminary themes and provided input to further refine the themes. Additionally, as we continued to refine the themes, a few new codes emerged in this re-coding process. Fifth, we further refined the themes by taking another broader look at the codebook and themes (Patton, 2015). Throughout the entire coding process, we used the constant comparison method anchored to the original data, which ensured that the codes and themes emerged from the data (Glaser, 1965). The final coding frame consisted of two primary themes (social-emotional support and independent living support) and 10 sub-themes with 30 total codes in the codebook.

Trustworthiness and Credibility

A colleague who is a researcher in the disability studies field performed intercoding with the primary author. Intercoding is conducted with a subset of data within qualitative studies, typically 10–25% of data units are selected for intercoder reliability (O'Connor & Joffe, 2020). For this study, the intercoder reviewed transcripts from 10% of the sample which consisted of three of the thirty interviews. The initial intercoding had 87–89% agreement of the coding frame, which exceeds the suggested standard of at least 80% agreement (O'Connor & Joffe, 2020). The intercoders discussed all the codes thoroughly until consensus was reached for total agreement in the end. We then updated and finalized the codebook from the discussion with the intercoder. We conducted member checking with four participants (20% of the sample), two people with IDD and two family members. This percentage was determined to balance the amount of burden placed on participants for the extra step of member checking and then need to check accuracy of the data for the research rigor (Birt et al., 2016).

Data Saturation

During data collection, the data were continually assessed to help gauge data saturation. Saturation occurs when there is no new information being gained that will add to the codes and themes as well as that the study is replicable at that point (Trotter, 2012). Reaching saturation occurs with a mix of *rich* data that builds the *quality* of the data as well as *thick* data that builds the *quantity* of the data (Fusch & Ness, 2015). In purposeful sampling, saturation is reached when respondents are sharing information that is redundant and no new information is being added. The data collection and analysis went hand in hand and as data was being collected, initial analysis was performed that helped inform decisions about subsequent data collection. Every few interviews were analyzed and preliminary codes were developed. After 10 interviews, the codes developed were consistently being used and no new codes were being added and there was sufficient rich and thick data to use for analysis. Also, the researchers determined that information that was consistently redundant was related to the purpose of the inquiry and therefore it was determined that saturation was reached.

Results

People with IDD and their chosen family members shared their perspectives on instrumental supports that highlights the integrated supports for people with IDD, including a mix of natural supports and formal services. The results highlight instrumental supports that consisted of four areas: (1) physical help with practical tasks such as chores, (2) medical needs to be healthy, (3) financial support, as well as (4) formal services and ways families provide support with these tasks. People with IDD in the study received natural supports from their family members for all four areas, including physical help, support to be healthy, financial support, and help with formal supports by families navigating the system of services for people with IDD. In addition to receiving support from their families, people with IDD also provided some reciprocal support to their families, specifically in two of the areas including physical help and support for healthy living, showing mutual exchange in their relationships.

Natural Supports from Family

People with IDD received many forms of instrumental support from their families including physical help with tasks like personal care, laundry, and cooking. Families also helped people with IDD to be healthy including support with medical needs as well as exercise and nutrition. Additionally, people with IDD received financial support.

Physical Help

People with IDD got a range of physical help from their family members such as with tasks of daily living, including personal care, laundry, and cooking. All ten participant needed some physical help, though some needed more than others. The physical support depended in large part on the disability and the support needs.

Support with personal care ranged from bathing and grooming to verbal reminders from family about things like hygiene, such as taking a shower or brushing their teeth. For example, Ethan needed help taking a bath. Erin's mom and sister helped her do her hair in the mornings before she went to work. Brian, Joey, Nelson, Sam and Erin's family provided reminders about things like hygiene, such as taking a shower or brushing their teeth. Sam explained how his family supported him, "So, I just get like reminders and stuff." Brian dressed himself and his family only interceded if his clothes were not appropriate for the situation or weather.

The amount of help needed for laundry varied. Four participants said their family always did their laundry. Four participants said they needed some help to do their laundry, though they also participated with things like folding and putting away. Two participants did their own laundry without any help from their family. For many families, supporting people with IDD to develop these skills with household duties was a way to increase the independence of the person with IDD.

All ten participants with IDD received help with cooking. For three participants, their family did all the cooking all the time and they did not participate at all. For seven participants, their family primarily did the cooking, though they could use the microwave or make a sandwich when necessary. Five participants with IDD did basic cooking, but they had fears related to using the stove to cook. For example, Judah's mom said, "he is afraid of like fire and just the whole using a stove. We've been practicing again…that fear is kinda getting in his way and we need to just keep working on it." Families helped with physical tasks including personal care, laundry, and cooking. They were invested in teaching basic skills in these areas to help people with IDD increase their independence and self-determination.

Being Healthy

People with IDD got help from their families to be healthy. All ten participants with IDD got help from their families to scheduling doctor appointments and be driven to visits. Much of the support that family members provided was scheduling appointments and providing transportation.

Medical Needs All ten participants with IDD received help from their families to schedule doctor appointments and be driven to visits. While Sam's mom still scheduled and drove him to his appointments, she no longer went in with him. This was an area of independence he achieved as he grew older. The support most participants with IDD got from their families with medical needs was related to logistics like scheduling appointments and transportation to medical visits.

Six participants received help from family members to take medications, mostly with reminders. For example, Joey clarified that his sister “helps me out with doing the medicine and everything that is diabetes. She, she helps me out with putting the medicine in order and I put them in the strip.” Judah explained, “Yeah, my parents will try to help me remember to take my medicine.” His parents have set up his phone to have alarms to help remind him too. Medical needs were an area where people with IDD received essential supports from their families to attend medical appointments and take medication.

Exercise and Nutrition Another part of keeping healthy was exercise and nutrition and people with IDD got support from their families in these areas. Four participants received support from their families related to weight management. Nelson shared, “Sometimes it’s hard, it really is, especially when it comes to food, I admit that that I eat almost anything and its and it’s just hard to lose weight sometimes, ya know.” He explained that his family is trying to support him in this area by encouraging him to eat healthy and exercise. Nelson’s mom expressed that the whole family worried about his weight and they have been trying to support him to be healthy. Sam explained, “Um, it’s mostly my mom just cooking healthy. And for exercise I, I just kind of have to like make myself do it. It can be really hard. And I don’t do it as much as I want to.” Sam’s mom stated: “I think one of Sam’s challenges is his weight. You know it’s, it’s hindering his ability to do certain things. And that’s something that we’ve tried to address and you know it’s, it’s, it’s a big deal for us.” One participant shared how her family members even exercised with her, which is very helpful. These examples highlight numerous ways family members provided support for people with IDD to be healthy such as help with medical needs as well as to eat healthy and exercise.

Financial Support

All ten participants with IDD received financial support from their families to help them with their money and finances. The concept of money was challenging for many people with IDD and support from their families was essential. Brian shared that his parents help him decide “what to spend it on and what not to spend it on.” Nick’s mom shared what so many family members echoed, “he doesn’t have a concept of money.” Therefore, many people with IDD turned to their families to help them make purchases, open a bank account, and keep track of their money. Four families talked about their worry with the person with IDD being victimized financially. Peter’s sister stated:

> He is not, he’s not independent financially. If you gave a twenty in and he should get ten back, like, even that simple part. Like, if you ask him the math

> equation, he'll answer correctly, but the money exchange, he won't, he won't really realize, like, he could be slipped a five.

Nelson's mom felt she really had to keep an eye on him in this area because, "I worry about him being victimized by people. And, yes he does, he he wants to please people. So of course, he wants to make people happy. So, he's willing to spend money on them or anything like that." Nelson knew his mom's concerns and stated, "She just wants me to be safe." The challenges and concerns related to finances were experienced by four participants and their families supported them in this area.

Three people with IDD were working to become more independent regarding their finances. For example, Tina had her own bank account and anticipated a credit card coming soon. Judah explained that, "at my school, we've done, we've practiced uh budgeting, I'm really good at it." He proudly shared that "I'm probably gonna have a bank account in the future." These participants were working toward increasing their financial independence with the support of their families, which was an important step for future planning.

Formal Services and Supports

Beyond natural supports, people with IDD relied on formal services and supports. Formal supports are those that are typically paid for by public funding, private insurance, or personally as out-of-pocket costs (National Council on Disability, 2012) and are usually provided by professionals (Shiba et al., 2016). People often have to apply and be eligible for specific formal support and services. Participants in the study discussed the importance of formal support and how critical families members roles were in navigating the formal support system so the person with IDD could receive these services.

Family Navigated Services

All ten participants with IDD in the study relied on family for help with accessing and navigating formal services. All family members navigated the formal supports for the person with IDD. This included getting information about and doing all the paperwork to sign up and maintain supports such as Social Security, SSDI, Medicaid and Medicare. It also included working with providers and case managers. A key support person explained the importance of the role of the case workers because they "oversees part of that support program because they help write the goals and everything else." Additionally, many people with IDD attended day programs and their family members had helped them find the day program and coordinated with the case manager and set up transportation. For some adults with IDD, the day program provided a place to go during the day to participate in activities with other adults with IDD where they were able to develop friendships and build skills.

Navigating the formal service system took time and was a tasks that families had to learn over time. In one family, the parents had divided up the workload with an understanding that the father did most of the paperwork, while the mother handled most of the calls that needed to be made. In this way, the family had split the role based on their areas of comfort and competence. Six of the participants had a guardian and four participants were their own guardian. Nick's mom explained that the primary reason she served as guardian of his estate was, "because he doesn't have a concept of money." Erin's family divided up the responsibilities for navigating her supports. Her dad did most of the paperwork and her mom made most of the calls. Her mom served as a representative payee for financial support. Brian's dad got paid as a support worker through the Medicaid Home and Community Based Services Waiver.

Rely on One Family Member

In some families there was one primary person who handled everything related to navigating the formal services and the other members in the family were unsure of what it required. For example, Peter's dad handled setting up all the formal services and both Peter and his sister were unaware of what it entailed or how to do it. Peter's sister stated: "My dad does everything for him. Um, but honestly, he knows nothing about it, nor do I." This is an example of information not being shared or passed down to others related to this role. If something were to happen to their father, there would be a huge learning curve for Peter and his sister to learn how to navigate the formal service system in order to maintain or increase the supports for Peter.

Seven participants with IDD did not really know or understand what their families did to help navigate their services and supports. Nelson said, "Mom helps out with that." When asked what she does to help, he stated, "That I am honestly not sure." Brian wasn't sure which services he received and he stated, "Um, that would be a good question to ask my dad cause I have no idea." While these participants did not understanding exactly what their families were doing, they knew they were supporting them with their services and supports.

Reciprocal Support

In addition to receiving instrumental supports, people with IDD also provided this type of support to their family members. Four participants shared ways they gave physical help to their family, mostly by doing chores around the house, as well as helping family members with their health, including providing support if a family member is sick.

Physical Help to Families

Physical help was primarily provided by participants with IDD to their families by doing chores around the house. When initially asked if they provided any physical support to their parents or siblings, six participants said no or don't know. However, later when asked about chores all ten participants shared about the chores that they provided such as helped clean the house, unloaded or put away groceries, set/cleared the table, washed dishes, took the garbage out, helped take care of pets, and more. Also, three participants helped their families by remembering where things were around the house and helped family members find them. For example, Tina, who needed a lot of physical support herself, responded that she did not provide her family with any physical support. Tina's dad described how she always knew where everyone and everything was and if someone wanted to know they just had to ask her. This attribute was very helpful to the family. He declared: "She's like, like a spy, just sitting there and you think she's sitting there on her computer, but she's listening to and watching everything. (Laughs)." The fact that her father recognized this as a helpful support showed that he valued her contributions to the family.

Healthy Living Supports to Families

Five participants described ways they helped family with other types of physical support such as helping family members with their health, including providing support if a family member was sick. This included help getting medicine from the cabinet or provide a reminder to take medicine, make some tea, or encourage their family to eat healthy and exercise. Brian revealed, "I remind my parents to take their pills every day." Brian's dad stated: "We don't need that help yet. (laughing) But at some point maybe." Yet, this father later talked about how his son helped him and his wife remember things as they were getting older, like taking their medicine when they were sick. When family members focus on helping the person with IDD be healthy, they themselves in turn enact more healthy behaviors as a way to model healthy living, wuh as eating healthy and working out. Also, one adult with IDD encouraged her family members to exercise. Tina's dad shared:

> She always wants me to exercise because she thinks I'm going to be more pleasant. If, like, if I'm going to work out or if I'm going for a bike ride, she's like "Good, go! Go for a long one," you know (laughs).

These examples show ways people with IDD play a role in helping their family members lead a healhty lifestyle.

Discussion and Implications

This inclusive and participatory research study used a qualitative research methodology to examine the perspectives of people with IDD on instrumental supports. Thirty virtual interviews were conducted using the dyadic interview method with 10 adults with IDD and 10 chosen family members. Findings showed that people with IDD received natural supports from their family in four areas including (1) physical help, (2) support to be healthy, (3) financial support, and (4) help with formal supports by family navigating the system of services for people with IDD. In addition to receiving support from their families, people with IDD also provided reciprocal support to their families in two of the areas, specifically support with physical help and healthy living. This reciprocal support shows the mutual exchange in family relationships and the contributions that individuals with IDD make which is often not acknowledged. Implications for practice and policy are shared along with directions for future research.

The current study showed the important role that family members play in instrumental support, especially integrating the informal and formal supports for the individual with IDD. The essential instrumental supports that families provided to people with IDD highlighted a mix of both natural and formal supports including the following four areas: physical help, help being healthy, financial support, and navigating formal services. These results are in line with other research, including the 2023 Family and Individual Needs for Disability Supports (FINDS) survey of over 3,000 caregivers of people with IDD which found that family caregivers were more likely to provide Instrumental Activities of Daily Living (IADLs) compared to any other type of supports (Lahti Anderson & Pettingell, 2023). The current study also found that people with IDD provided reciprocal support to their families in two of the four areas: physical health and help with healthy living. The supports individuals with IDD provided to their families were equally important and often not as easily recognized. Using the life course theory conceptual framework, people with IDD and their families have interdependent relationships of support that change over their lifetimes. For example, families provided critical instrumental support to people with IDD as they transition to adulthood. Yet, people with IDD can play a critical role in reciprocating instrumental support at a later point in life, especially as parents age. These supportive exchanges over the life course within families are significant and have implications for policies, systems, and future directions in research.

Support from Family

Physical Help

All ten participants with IDD in the study received some type of physical help from their family members. This included help with *personal care tasks* such as bathing and grooming as well as *daily living tasks* such as doing laundry and cooking. Families provided a lot of *verbal reminders* for people with IDD to do personal care tasks such as prompting to brush their teeth. The FINDS survey confirmed that 68% of caregivers provided at least one type of support for activities of daily living (ADLs) including support with personal hygiene and daily tasks (Lahti Anderson & Pettingell, 2023).

Implications for this are that family members spend extensive amounts of time on physical support to people with IDD and as a result they need more support for their caregiving role. Respite is underutilized by families and can provide a break to help family caregivers rest and rejuvenate so they can continue with their caregiving duties (Leocadie et al., 2018). Additionally, ways to reduce reliance of people with IDD on family members for these types of supports could decrease the family member responsibilities and increase the independence and self-determination of the person with IDD. For example, teaching basic skills to people with IDD such as laundry and cooking through more educational programs that target this population. Also, technology could be used in new and exciting ways to support people with IDD. A study exploring use of smarphones by adults with ID found the smartphones could effectively provide prompts to help participants successfully engage in daily activities (Lancioni et al., 2017).

Health Supports

Every participant with IDD received help from their families to be healthy. This included help with *medical needs* as well as support with *exercise and nutrition*. Families' primary role with medical needs included scheduling medical appointments and providing transportation to get to appointments. Family members also provided a lot of help with medications, most often providing verbal reminders to individuals with IDD to take their medicine. Half the participants with IDD talked about ways their families supported them to exercise and make healthy food choices. These findings reinforce the results of the 2023 FINDS report which found that family caregivers provided extensive health supports to people with IDD, most helping coordinate health care (91%) and managing medications (84%) (Lahti Anderson & Pettingell, 2023).

Implications for health supports provided by families include the need for more interventions that help family members in their caregiving role. In a focus groups study, family members of people with IDD discussed the need for more information about the health trajectory of their family member with IDD, especially as they age (Krahn et al., 2023). Also, technology interventions, such as the use of smartphones or smart watches, could promote independence of the person with IDD and diminish the responsibilities of family caregivers in these areas. While there a medication management apps, there are few designed for people with IDD. The interactive Mobile Health and Rehabilitation (iMHere) system specifically targets individuals with DD (Dicianno et al., 2016). Salgado and colleagues (2018) reviewed medication management apps and identifies features that were most effective for young adults with DD. There is potential for more technological interventions related to health support for people with IDD.

The families' role in helping individuals with IDD with their diet ensured they kept healthy and safe and could even be lifesaving due to certain food allergies. However, families were often not given support and training in the fundamentals of nutrition to help them in this role (Ptomey & Wittenbrook, 2015). More health and nutrition programs should be targeted to people with IDD and their families to help them both improve healthy living. For example, the HealthMatters™ Program has developed an evidence-based health promotion program for people with IDD and their supporters that should continue to be disseminated so more people can access it, including families (Marks et al., 2013).

Financial Support

All ten participants with IDD received financial support from their families to help them with their money and finances. Families provided essential support in this area since the concept of money was challenging for most participants with IDD. Three people with IDD were trying to build their financial skills with the support of their families so they could be more independent in this area. This is reinforced by the FINDS report which found that for caregivers of people with IDD, 79% provided financial support and 84% provided support with money management (Lahti Anderson & Pettingell, 2023).

Implications include the need for more financial literacy programs targeted to people with IDD. Part of the challenge, as shown in other research, was that most people with disabilities have low financial literacy and were often not provided the inforamtion or opportunities to learn about money and get experience with financial transactions (Goodman et al., 2017). Very little research focuses on personal financial literacy supports that families provide and this is an area that requires further attention. Financial literacy and planning are areas that many people with IDD can become more independent in if given the right supports (National Disability Institute, 2018). The National Disability Institute (NDI) is a national nonprofit focused exclusively on financial education and empowerment of people with disabilities. With additional funding and commitment in this area, NDI is primed to provide more financial literacy education to people with IDD to help them learn these life skills and reduce this role for families. Financial literacy programs specifically for people with IDD could help to grow their skills in these areas so they could be more independent and would not need as much support from their families. More financial support programs are needed to teach people with IDD in accessible ways about how to manage their money safely and responsibly.

Formal Supports

All ten participant with IDD relied on their family members to help with their formal supports. Family members helped them navigate the formal support system by helping get information about supports and signing them up for Social Security, SSDI, Medicaid and Medicare. In many families there was one primary person who handled all the required paperwork and processes related to formal support. The other family members, especially the individual with IDD, were unaware of what was involved regarding getting and maintaining formal supports. If that family member was no longer able to manage the formal supports, the other members would not know what to do. This highlights the importance of families discussing this area and communicating information so more than one family member is knowledgeable about how to navigate the formal supports. In conjunction with this study's results, the FINDS report found that more than half of all family caregivers (59%) needed help with navigating services for their family member with IDD. Additionally, almost two-thirds (60%) of family caregivers of people with IDD reported a need for more information about formal services (Lahti Anderson & Pettingell, 2023).

Implications are that there is a need to assist families in navigating the complicated system of supports and services. While participants with IDD were aware that their families helped them navigate their formal services, they had no idea what their families did, and they were not part of helping with these activities at all. The formal service system was very complicated to navigate and people with IDD relied fully on their parents and siblings to figure out what was available to them and how to get access to the services they needed. There was no guide or roadmap for how families navigated this realm so the services the person with IDD received depended on how well their parents and siblings were able to find and understand information and also advocate to get the services the person with IDD needed. Families need more support related to navigating the formal support system. For example, there could be family navigators assigned to each family to provide personalized support for the whole family in navigating the services. There are a few models of this that could be expanded across the country to provide a more seamless system (Llano et al., 2020).

Reciprocal Support

The reciprocal support that people with IDD provided to their families was found in two areas of support in this study, (1) physical help and (2) help with healthy living, though not for financial support, and navigating formal services. Using the life course theory conceptual framework (Graff et al., 2008), people with IDD and their families have interdependent relationships of support that change over their lifetimes. There is a give and take of support throughout different ages and stages in life. In general, people with IDD receive more support from their families when they are younger and they give more support to their family members as they get older, especially as their parents age.

Physical Help

All ten participants with IDD provided some type of help with physical tasks around the house. Initially, six participants did not think they provided any phsycial support to their families, yet upon further discussion, they realized they did provide some physical help with tasks around the house. These chores included cleaning, putting away groceries, setting/clearning the table, washing dishes, taking out the garbage, pet care, and more. Additionally, a few participants with IDD helped their family members find things when they couldn't remember or didn't know where something was located. These findings are reinforced by a study by Truesdale and colleagues (2021) that show how people with IDD provide increasing supports to their aging parents.

Implications include that the reciprocol support that people with IDD provided to their families with physical help will likely increase as parents age. People with IDD can help with household chores that may become too physically difficult for parents as they get older. The physical help that people with IDD provided could allow aging parents to remain living in their home without outside support or nursing assistance for longer than they could otherwise.

Healthy Living Supports

Half of the participants with IDD shared ways they helped their family members be healthy. This included helping their family members when they were sick such as providing reminders for them to take their medicine and making tea. Also, people with IDD provided support for their family members to lead a healthy lifestyle by encouraging them to exercising and eating nutritious food. When family members focused on helping the person with IDD be healthy, they themselves enacted more healthy behaviors as a way to model healthy living. This tangential positive effect on health from helping their family member with IDD be healthy is an area that could be explored more.

Implications are that health interventions should include both the person with IDD and family members to support each other together in light of these relationship dynamics. Also, these results indicate that people with IDD may provide health supports to their aging parents that could keep them from needing outside instrumental support, such as assisted living or nursing care support. This is an area of research that requires further exploration (Heller et al., 1997). These supportive exchanges over the life course within families are significant and have implications for policies, systems, and future directions in research.

Policy and Systems Implications

People with IDD rely on instrumental supports with a mix of natural supports and formal supports to live their lives. Families of people with IDD are crucial for the natural supports they provide as well as the help they give to ensure formal supports are in place and maintained. Families in this study provided most instrumental supports to participants with IDD. This constant and daily support can be vital for people with IDD to lead inclusive, connected, healthy, and meaningful lives. Families need more support so they can continue to provide the critical support they give to the person with IDD.

The need for more support to families of people with IDD has implications for policy and system changes. Families can be helped by either providing more direct support to them to help alleviate stress and burnout or by reducing the amount of support for which families are responsible, including by providing more direct supports to people with IDD. A combination of these strategies could work best and can be addressed through policy and systems change.

Direct support to families for their caregiving roles currently occurs in a patchwork manner throughout the country (Hecht & Reynolds, 2012). Depending on the state someone lives in and the particular supports and services available in that state, a family may or may not have the supports and services they need to help the whole family. For example, each state has their own Medicaid waiver that specifies different eligibility requirements and services available through it. Families have difficulty navigating the information to understand what could be available to meet their needs. Another example is related to respite, a direct service that is beneficial to family caregivers and gives them a short break for their caregiving role. Each state has different funding streams, eligibility requirements, and processes for accessing respite (Leocadie et al., 2018). Having a more streamlined system that provides more direct supports to families in a way they understand could increase outcomes for people with IDD and the whole family.

Creating systems and policies that reduce the amount of support that families are responsible for can help the whole family. As a result, family members will be able to focus their time and energy on the most vital supports that people with IDD need; and families will have more time to take care of themselves and the other members in the family. One way to reduce the complexity for families could be to implement family navigators across the country to help families understand the complicated systems of supports and services for people with IDD. Having a dedicated person available to gather information and explain processes would save families much time and energy. Some states have successful family navigator programs (Llano et al., 2020) that could serve as a model to replicate across the country. The RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act was passed in 2018 and brings together stakeholders to put together a national family caregiving strategy that can identify actions that can be taken at the national and local levels to better support family caregivers. The 2022 National Strategy to Support Family Caregivers highlights actions that can be taken by government organizations and the private section around five priority areas which hold promise to activate change (ACL, 2023).

Policies should consider the support people with IDD provide to their families. More should be explored about the ways people with IDD are helping to support their aging caregivers remain in their family home instead of needing outside supports such as assisted living or nursing home care. People with IDD can give instrumental support such as help with chores around the house and help for healthy living that may allow aging caregivers to stay in their homes longer than they otherwise would. This support from people with IDD to aging parents can also alleviate stress and responsibilities for the other siblings in the family. For example, if a person with IDD lives with their aging parents, their sibling can determine what supports the individual with IDD could help with so they do not have to step into that role or pay for outside care, such as laundry, cleaning, and cooking. These important instrumental supports that people with IDD provide should be explored further as there are relevant policy and practice applications related to reciprocal support that people with IDD provide to their families.

Limitations

The current study had some limitations that are important to recognize. First, doing research in the time of the COVID-19 pandemic presented some challenges. Due to COVID-19, the interviews were switched from in person to remote and conducted on Zoom. This may have excluded some people that did not have the technology to participate in a remote interview. While a phone option was available for people to call in and most people had access to the phone, not everyone had the capability to connect to the internet or show/see video and see the visual support. Additionally, it was not possible to get a full sense of participant's environment except for a small portion of where their camera showed for those using camera. For example, for some people there was background noise and a sense that someone else was in the room which might have been distracting or influenced the responses of some participants.

Second, the demographics of the participants may have limited the findings of the study. Specifically, the sample did not include any participants who were Black or African American and did not capture cultural differences among Hispanic participants. Future studies could be designed to more specifically examine racial and cultural differences that people with IDD perceive related to family support. Additionally, the majority of the participants were male (80%) and there may be gender differences that were not fully captured in this study. Also, the study only focused on adults with IDD who lived at home in Illinois. The data only captured information about the supports provided from family members, without gathering information about additional supporters in the lives of people with IDD. These demographic limitations should be taken into consideration with the findings.

Third, there were limitations to the participatory approach used with the Community Advisory Committee members. Historically, individuals with IDD have been prevented from participating as partners in research projects with discriminatory ideas that they do not have the expertise to adequately contribute. As a result, many people with IDD have little experience being part of a research study and providing guidance to researchers (Buck et al., 2024). For example, the CAC members for this study were new to participating in research and this lack of experience may have limited their confidence in sharing all their thoughts and ideas to contribute to the study. Also, the personal relationship that the researcher had with CAC members may have added some bias to the process.

The size of the sample was small with only ten participants with IDD and ten family members they chose. Also, with the use of snowball sampling the participants are likely from similar social networks. Therefore, the findings are not generalizable which is common for qualitative research (Leung, 2015). This qualitative study provides rich descriptive data about a topic that should be explored further and helps to lay a foundation for more knowledge to be produced in the future.

Future Directions in Research

More research is needed about integrated supports from the perspectives of people with IDD and their families. Understand how outcomes are impacted based on the balance of formal services and natural supports could inform interventions for people with IDD and their families. Also, learning more about ways to expand the natural supports of people with IDD, while providing support to the people who provide natural support, is essential due to the limitations of the current formal service system. Conducting participatory research is an important way to include people with IDD in the research process on topics related to their lives. The use of a Community Advisory Committee comprised of five adults with IDD enriched this study and future studies could benefit by using a similar process.

Future research could examine ways people with IDD are providing support to their aging caregivers. This is an area that is not acknowledged and there are major policy implications of this. Additionally, future research could look at the ways families provide support for navigating the formal services. Interventions could be developed to better include people with IDD in navigating their own formal support.

There may be more supports that people with IDD provide to their families that are undiscovered. Focusing on what the person with IDD does to provide support to their families is novel and an area where both people with IDD and their families are not used to recognizing and vocalizing. More research is needed on instrumental supports to better understand ways people with IDD may be providing support to their families that is unacknowledged.

Appendix A: Semi-Structured Interview Guide

1. Please tell me a little bit about your family, including your parents and siblings.
2. How do your parents and siblings support you? What types of things do they do to help you out?
3. What else do you wish your family did to help you?
4. Is there something you do NOT want your family to help with?
5. Are you happy or unhappy with the support you get from your family? Please explain.
6. How would you describe your level of support needs? (i.e. the amount of help you need)
   a. 1-None 2-A little 3-Some 4-A lot 5-Don't Know.
   b. Can you tell me more about the help you need?
7. You have told me a lot about the help you get from your family. Now, I want to ask you about the help you GIVE to your family members. What types of support/help do you GIVE to your family?
8. How has your family planned for the future?
9. Is there more you want to share about your family and the help you get and give?

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Author Contribution Principal Investigator.

Declarations

Compliance With ethical standards **Research Involving Human Participants**: This study was approved by the University Institutional Review Board and in accordance with the Declaration of Helsinki. The Human Investigation Committee (IRB) of University of Illinois Chicago approved this study.

Informed Consent Informed consent was obtained prior to the interviews with participants.

Conflicts of Interest The authors have no competing interests to declare that are relevant to the content of this article.

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