Intellectual and Developmental Disabilities

Examining Support Networks Among Individuals with Intellectual and Developmental Disabilities

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Corresponding Author:	Meghan M Burke, PhD Vanderbilt University Nashville, TN UNITED STATES
First Author:	Megan Best
Order of Authors:	Megan Best
	Meghan M Burke, PhD
	Catherine Arnold
Manuscript Region of Origin:	UNITED STATES
Abstract:	Understanding the support networks of individuals with intellectual and developmental disabilities (IDD) is important given that adults with IDD are outliving their parents—their primary caregivers. We surveyed 601 adult siblings of individuals with IDD to identify: Who provides caregiving support to adults with IDD?; Do the types of caregiving support vary in relation to the support network role?; and To what extent do individual, sibling and family characteristics correlate with the size of the support network?. On average, individuals with IDD possessed small support networks with most support networks comprised of family members (primarily parents). Individuals with Down syndrome (versus autism) reported larger support networks. Implications for research, practice, and policy are discussed.

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Abstract

Understanding the support networks of individuals with intellectual and developmental disabilities (IDD) is important given that adults with IDD are outliving their parents—their primary caregivers. We surveyed 601 adult siblings of individuals with IDD to identify: Who provides caregiving support to adults with IDD?; Do the types of caregiving support vary in relation to the support network role?; and To what extent do individual, sibling and family characteristics correlate with the size of the support network?. On average, individuals with IDD possessed small support networks with most support networks comprised of family members (primarily parents). Individuals with Down syndrome (versus autism) reported larger support networks. Implications for research, practice, and policy are discussed.

keywords: siblings, intellectual and developmental disabilities, support network

Examining Support Networks Among Individuals with Intellectual and Developmental Disabilities

As individuals with intellectual and developmental disabilities (IDD) age, their parents and/or their siblings often fulfill supportive roles, including caregiving roles (Hodapp et al., 2017; Lee et al., 2020). While research has been conducted to identify service and support needs of adults with IDD (Acharya et al., 20016), we know little about their support networks—the group of individuals that supports the person with IDD. Support networks may be comprised of paid supporters (e.g., personal support workers, respite workers) and unpaid supporters (e.g., parents, siblings, friends); to that end, support networks often reflect integrated (i.e., paid and unpaid) supports (Reynolds et al., 2018). Expanding support networks is critical so the onus of support does not all fall on one individual (e.g., the parent or the sibling without a disability). Support may be characterized as discrete tasks such as direct assistance or financial support; support may also be characterized more abstractly (e.g., help with decision-making). By understanding the composition of support networks, we can better address the needs of individuals with IDD and their families into adulthood. Thus, the purpose of this study was to characterize support networks of individuals with IDD.

At the most basic level, it is important to identify the members of an individual's support network. In a study of natural supporters for adults with IDD, Sanderson and colleagues (2017) identified the following supporters: siblings without IDD, parents, and other family members. In addition, there was a write-in response about "other supporters"; from these responses, the following types of supporters emerged: agencies, professionals, friends, staff, acquaintances, caregivers, schools, coaches, and churches. Notably, their study was primarily focused on unpaid natural supporters. It may be that unpaid supporters assume multiple caregiving roles; for example, siblings may be compound caregivers by caregiving for their aging parents, brothers and sisters with IDD, and/or own children (Lee et al., 2020). By expanding the examination of supporters to include paid and unpaid individuals, we may gain a more comprehensive understanding of support networks.

It is also important to understand the types of support provided by certain individuals. In a national sample of siblings of individuals with IDD, Burke and colleagues (2012) found that caregiving tasks often all fall on one sibling without a disability in the family. Even when there were multiple siblings without disabilities in a family, the tasks were not dispersed across the siblings. By putting all of the caregiving tasks on one individual, there is a likelihood for caregiving burnout and potential resentment toward other siblings in the family (Halliwell et al., 2017). However, their study did not specifically ask about supports provided by other individuals—they only asked about the types of support provided by the adult sibling respondents. It may be that, by probing the types of support provided by individuals within the support network, we can identify who is and is not assisting with certain tasks and, accordingly, intervene with individuals who are not helping share the support loads.

It is also important to identify the correlates of the size of the support network. Given the large roles that parents play in caregiving for their adult offspring with IDD throughout their lifespans (Sanderson et al., 2017), one would expect that parent caregiving ability would strongly increase the support network. In addition, characteristics of the person with IDD may relate to the support network size. Individuals with IDD with greater maladaptive behaviors and fewer functional abilities may require greater supports (Lee et al., 2019); thus, their support network may be larger. Notably, while their needs may be greater, it is possible that their support network may be small due to financial and/or staffing issues (Owen et al., 2015). Accordingly, there may be a greater burden on siblings and parents to fill in the gap. The type of disability may also impact support network size. The Down syndrome advantage (i.e., having more positive caregiving experiences when the person with IDD has Down syndrome versus other types of disabilities, Esbensen et al., 2010) may include having larger support networks. In a study of sibling closeness and relationship quality, Hodapp and Urbano (2007) found that siblings of individuals with Down syndrome (versus autism) reported more positive and close relationships. Thus, individuals with autism (versus Down syndrome) may have smaller networks.

Other potential correlates for support network size may relate to the sibling without a disability. Many siblings report enjoying meeting other siblings of individuals with IDD and belonging to the disability community (Zucker et al., 2022). Such peer support may include larger support networks. Racial background may also relate to the support network. Many individuals from underrepresented backgrounds value familial capital (Yosso, 2005). Thus, it may be that siblings from underrepresented backgrounds have greater support networks. By identifying who has large support networks, we can more closely examine these families and try to replicate protective factors that seem to facilitate larger networks. In addition, by identifying correlates we can identify individuals prone to smaller support networks and thereby target them for individualized support.

As individuals with IDD outlive their parents, it seems that siblings may likely fulfill supportive roles, including caregiving roles (Hodapp et al., 2017). At the same time, siblings report being nervous (e.g., feeling unprepared or anxious) to assume caregiving roles (Chiu, 2022). When a support network exists, individuals with IDD demonstrate improved outcomes (e.g., gainful employment, independent living, and post-secondary education, Sanderson et al., 2017) and their siblings demonstrate better physical and mental health (Marquis et al., 2019).

Examining a support network is critical as individuals with IDD may use paid and unpaid supports—the latter of which may be more common given that most individuals do not receive formal DD services (Burke et al., 2018). Even as individuals with IDD are starting to live in the community (versus congregate care or in the family home), unpaid supports continue to play important roles in supporting adults with IDD. In this study, we explored the support networks of individuals with IDD. Using a national sample of siblings of individuals with IDD, we had three research questions: 1) Who provides caregiving support to adults with IDD?; (2) Do the types of caregiving support vary in relation to the support network role?; (3) To what extent do individual, sibling and family characteristics correlate with the size of the support network? In the survey, we often used the term "caregiver" or "caregiving" to describe the support provided to individuals with IDD. However, we acknowledge the controversy around the term "caregiving/caregiver" and extant research suggesting that "caregiver" may not be the appropriate way to characterize supports provided from siblings to their brothers and sisters with IDD (Lee et al., 2018). Thus, when describing the survey and its items, we retained the original language of "caregiver" or "caregiving" in this manuscript; when writing about the network of the sibling, we termed it "support network".

Method

Positionality

Our research team was comprised of three individuals with experience in the disability field. Notably, two of the individuals identified as siblings of people with IDD. Their lived experiences helped ensure the relevance of the survey to siblings. All three individuals identified as White. While the survey was reviewed by individuals from diverse racial backgrounds, the limited racial diversity among our team may have influenced the cultural responsiveness of the research design.

Participants

In total, 601 adult siblings of individuals with IDD participated in this study. To be included in this study, participants needed to be: over 18 years of age; willing to complete a web-based survey; and have an adult brother/sister with IDD. On average, participants were 39.43 years of age (*SD* = 13.99, range from 20 to 79). Altogether, 12.31% of participants reflected underrepresented backgrounds. Participants reflected 46 states and Washington D.C., excluding Delaware, Hawaii, North Dakota, and Rhode Island. Most participants were female (88.35%, *n* = 531) and nearly half were married (46.09%, *n* = 277). On average, the brothers/sisters with IDD were 31.70 years of age (*SD* = 15.01, range from 3 to 87). See Table 1.

Recruitment

Recruitment reflected a multi-pronged approach. For example, we sent emails and recruitment flyers to the Sibling Leadership Network and its statewide chapters as well as local and state disability organizations; also, we targeted agencies and organizations that served underrepresented individuals with disabilities and their families. In addition, we distributed the recruitment flyer to the state and local chapters of The Arc and the 67 University Centers for Excellence in Developmental Disabilities. We also sent e-mails with the recruitment flyer to the 7,843 agencies listed in the Yellow Pages for Kids with Disabilities. Agencies included: service providers (*n* = 3,025), advocacy and legal agencies (*n* = 1,725), schools and educational agencies (*n* = 1,386), nonprofit disability agencies (*n* = 1,271), and parent support groups (*n* = 436). No compensation was provided for completing the survey.

Procedures

All study procedures were approved by the University Institutional Review Board. We developed the Adult Sibling Survey using a series of steps. First, we reviewed the literature about siblings of adults with IDD to inform the survey (e.g., Lee et al., 2019; Burke et al., 2012). Then, we received feedback from three faculty members with expertise about adult siblings of individuals with IDD, five professionals in the IDD field, and ten siblings of individuals with IDD. Upon receiving their feedback, we revised the survey. We piloted the survey with five siblings of individuals with IDD. Revisions were minimal (e.g., adding branching logic and correcting typographical errors). For example, we revised a multiple-choice question to a ranked order question; also, we added a response option with respect to family size.

The survey was put onto a secure survey platform, Qualtrics. The survey was available from September 2018 to May 2019. On average, the survey took 20 to 25 min to complete. Although there was a hard copy option for the survey, all surveys were completed electronically. To access the survey, participants clicked on a uniform resource locator provided in the recruitment flyer. Responses were stored in Qualtrics Survey Software and downloaded periodically to guard against computer malfunctions.

Measures

Support Network

Participants were asked who provides caregiving support to their brothers/sisters with IDD: *Themself, Parents, Other Siblings, Relatives, Friends, Community Members, Paid Employees,* and *Other Individuals*. For each role, there were two response options: (0) *does not provide support* and (1) *provides support*. We summed each potential support person to create a continuous variable ranging from 0 supporters to 8 supporters. The supporter roles were identified based on prior research (e.g., Sanderson et al., 2019). If a participant indicated "other individuals", there was an opportunity to write about the other caregiving supporter. Of the 601 participants, 110 participants selected "other" as a response (*n* = 110). Within the response, some participants wrote more than one other caregiving supporter. Altogether, there was a total of 122 write-in responses.

With the exception of sibling respondents, for each supporter, participants answered whether the supporter provided each of the following types of support: Direct Assistance, Financial Assistance, and Help with Major Decisions about Care. Each type of support had two response options: (1) *not at all* and (2) *some*.

Functional Abilities of the Individual with IDD (Activities of Daily Living, Seltzer & Li, 1996).

Comprised of 15 items, the Activities of Daily Living scale measures the functional abilities of individuals with disabilities. Participants were asked, "Can your brother/sister with a disability perform the following activities with total help, some help, or without help?" Activities included housework, laundry, and prepare meals. For each item, there were three response options: (1) *without help*; (2) *with some help*; and (3) *with total help*. Variables were summed into a cumulative score ranging from 15 to 45, with higher scores indicating less functional abilities. Prior studies with siblings of adults with IDD have reported high reliability for this scale (e.g., α = .93, Lee et al., 2019). For this sample, Cronbach's alpha was .94.

Maladaptive Behaviors of the Individual with IDD (Scales of Independent Behavior-Revised [SIB-R], Bruininks et al., 1996)

The SIB-R reflects internalizing, externalizing, and asocial behaviors. Specifically, behaviors include: self-injurious behavior; disruptive behavior; unusual or repetitive habits; socially offensive behavior; withdrawal or inattentive behavior; and uncooperative behavior. Participants rated the frequency and severity of each behavior. The frequency of the behavior was gauged by a six-point Likert scale: (1) *never*; (2) *less than once a month*; (3) *1-3 times per month*; (4) *1-6 times per week*; (5) *1-10 times per day*; and (6) *1 or more times per hour*. The severity of the behavior was measured by a six-point Likert scale: (1) *does not apply*; (2) *not severe*; (3) *slightly severe*; (4) *moderately severe*; (5) *very severe*; and (6) *extremely severe*. In a previous study using the SIB-R, there was high reliability (Cronbach's alpha = .81, Burke & Heller, 2016). In this study, reliability was high for each subscale (α's = .80).

Parent Caregiving Ability (Burke et al., 2012)

Participants were asked one question to gauge their parents' caregiving ability: "How well are one or both of your parents able to take care of your brother or sister with disabilities?". Response options included: (1) *not applicable-deceased*; (2) *poor*; (3) *fair*; (4) *good*; (5) *very good*; and (6) *excellent*. This item has been used in prior studies to measure parent caregiving ability (Burke et al., 2020; Casale et al., 2021; Lee et al., 2019).

Independent Variable: Disability Connectedness (Author, in press)

Via ten items, participants answered questions about their degree of insiderness in the disability community (i.e., their feelings of connectedness to the disability community). Items included "To what extent have you devoted time to disability-related groups, causes or activities?" and "To what extent do you have friends or socialize with parents of individuals with disabilities or individuals with disabilities themselves?". Response options ranged from (1) *not at all* to (5) *very much so*. In the original study establishing the reliability of the measure, there was high reliability (α = .88, Author, in press). In this study, reliability was also high (α = .94).

Presence of Down Syndrome

Participants were asked "Does your brother/sister have Down syndrome?". Response options included: (0) *no* and (1) *yes*.

Presence of Autism

Participants were asked “Does your brother/sister have autism?”. Response options included: (0) *no* and (1) *yes*.

Race and Ethnicity

Participants were asked to check all that apply in terms of their background: White, African American or Black, Hispanic or Latino, Asian, or Other. For this study, the variable to describe background was dichotomized as: (0) *an underrepresented background* and (1) *White*.

Analyses

First, we conducted preliminary analyses. Specifically, we conducted descriptive statistics to familiarize ourselves with the dataset. We examined the distributions of the variables via histograms, skewness and kurtosis; variables were normally distributed. Per the variance inflation factor and a correlation matrix (see Table 2), we did not identify multicollinearity among the independent variables. After conducting our preliminary analyses, we then conducted the primary analyses by research question. We conducted descriptive statistics to answer our first two research questions about the composition of the support network and the types of caregiving provided by the network members. To compare differences in the frequency of each supporter, we conducted Cochran’s Q analyses and, if significant, we conducted McNemar’s analyses as follow-ups. For the write-in responses for the “other” caregivers, we conducted frequency counts of the “other” supporters. Specifically, one research team member clustered the other supporters into groups. Then, another research team member reviewed the groups. Together, they agreed upon the groups and conducted frequencies of the groups. For the third research question about the correlates of the support network size, we conducted a linear regression.

Results

Size of the Support Network

On average, the size of the support network was 2.65 (*SD* = 1.39) with a range from 0 supporters to 7 supporters. Overall, there were significant differences in the frequency of each supporter ($X^2 = 1102.50$, $p < .001$). Follow-up McNemar analyses revealed significant differences among specific roles. For example, the sibling participant was significantly less likely to be a supporter compared to their parents ($p < .001$) and more likely to be a supporter compared to: other siblings, relatives, friends, community members, paid caregivers, and others (*p*'s < .001). Parents were significantly more likely to be supporters compared to all other individuals (*p*'s < .001). Other siblings were significantly more likely to be supporters compared to relatives, friends, community members, paid caregivers, and others (*p*'s < .01). Relatives were significantly more likely to be supporters than friends ($p = .05$), the community ($p < .001$), and others ($p < .001$). However, relatives were less likely to be supporters than paid caregivers ($p < .001$). Friends were significantly more likely to be supporters than the community ($p < .001$) but less likely than paid caregivers ($p < .001$). Community members were less likely to be supporters than paid caregivers ($p < .001$). Paid caregivers were significantly more likely than others to be supporters ($p < .001$). Altogether, siblings themselves and their parents were frequent supporters with 61.73% and 74.04% serving in the networks. To a lesser extent, paid workers (39.77%) and other siblings (31.95%) were supporters. To a much lesser extent, relatives (19.47%), friends (15.64%), other individuals (12.31%) and community members (9.82%) served within the support networks. See Table 3.

There were several write-in responses about other supporters. The "other" responses included: the sibling-in-law of the person with IDD (31.15%, $n = 38$), paid worker (31.15%, $n = 38$), niece or nephews (9.02%, $n = 11$), other sibling (6.56%, $n = 8$), the significant other of the person with IDD (5.74%, $n = 7$), parents (3.28%, $n = 4$), other (1.64%, $n = 2$), and friends (0.82%, $n = 1$). A few participants responded that their brother/sister with IDD either did not have any additional supporters or they were their own caregivers (9.84%, $n = 12$), while one participant stated “N/A” (0.82%). See Table 4.

Types of Caregiving Support

Across the supporters, there were significant differences with respect to direct care ($X^2 = 828.59$, $p < .001$). See Figure 1. Most striking, parents provided significantly greater direct assistance in comparison to all other supporters (*p*’s < .001). Of the paid workers, 36.44% provided direct assistance which is significantly more than other siblings, relatives, friends, the community, and others (*p*’s < .001). Other siblings and relatives provided significantly greater direct assistance compared to friends, community members and others (*p*’s < .01). Finally, friends provided significantly more direct assistance than community members and others (*p*’s < .01).

With respect to financial assistance and help with major decisions about care, there were significant differences across supporters ($X^2 = 1459.39$, $p < .001$). Similar to direct assistance, parents provided significantly more financial assistance compared to all other supporters (*p*’s < .001). Siblings and relatives provided significantly more financial assistance compared to friends and community members (*p*’s < .01). Community members and friends provided significantly more financial assistance compared to paid workers and others (*p*’s < .01).

With respect to help with making major decisions about care, there were also significant differences across supporters ($X^2 = 1351.33$, $p < .001$). Parents provided significantly more assistance with major decisions compared to all other supporters (*p*’s < .001). Other siblings provided more assistance with decisions compared to relatives, friends, community members and others (*p*’s $< .001$). Paid workers provided more assistance with major decisions compared to relatives, friends, community members, and others (*p*’s $< .001$).

There were also within supporter variations in relation to caregiving responsibilities. Parents were significantly more likely to provide help with major decisions about care than financial assistance (65.06% versus 63.73%, $X^2 = 10.09$, $p < .001$). Other siblings were significantly more likely to provide direct assistance (25.12%) in comparison to help with major decisions and financial assistance (15.97% and 7.82%, respectively, $X^2 = 126.89$, $p < .001$). Relatives were significantly more likely to provide direct assistance versus financial assistance or help with major decisions (16.47% versus 5.82% and 5.66%, $X^2 = 100.27$, $p < .001$). Friends were significantly more likely to provide direct assistance (11.98%) compared to financial (1.83%) and help with major life decisions (1.99%), $X^2 = 101.69$, $p < .001$. Relatives, friends, community members, paid workers and others were significantly more likely to provide direct assistance (compared to financial and help with decisions, *p*’s $< .001$). See Table 5.

Correlates of the Support Network

Altogether, the regression model was significant explaining 15.7% of the variance ($F = 12.96$, $p < .001$). Specifically, when parents were more able to care for the person with IDD, there was a positive, significant correlation with the size of the support network ($p < .001$). Further, when the sibling was more connected to the disability community, there was a positive, significant correlation with the size of the support network ($p < .001$). There were also significant variables in relation to characteristics of the person with IDD. When the individual with IDD had greater maladaptive behaviors and fewer functional abilities, there were significant, positive correlations with the support network size (*p*’s $< .001$ and $= .03$, respectively). Further, when the person with IDD had Down syndrome, there was a significant, positive correlation with the support network size (*p* = .04). Conversely, when the person with IDD had autism, there was a significant, negative correlation with support network size (*p* = .002). Notably, there was a marginally significant effect with racial background (*p* = .07) with White participants reporting significantly greater support networks. See Table 6.

Discussion

In our study, we examined support networks for individuals with IDD. We had four main findings. First, parents matter. Most participants reported that they and their parents provided the most caregiving support to their family members with IDD. Given that individuals with IDD are outliving their parents (Brennan et al., 2018), this is concerning as, once the parents pass, the support network will shrink by half. This finding is underscored by the regression results indicating that perceptions of poor parent caregiving correlates with smaller support networks. Increasing support networks is critical to ensure that the caregiving work does not all fall on only one or two individuals.

Second, there is a strong family effect with most support network members and caregiving tasks being completed by parents, siblings and relatives. Specifically, most tasks fall onto one sibling—the participant. It is likely that siblings of individuals with IDD identify as compound caregivers, or act as caregivers to the sibling with IDD, as well as others, such as their own children and/or their aging parents (Hodapp et al., 2017). The impact of providing primary caregiving to a sibling with IDD, as well as others, could lead to greater caregiving burden, increased family distress, and greater risk for poor health and well-being (Lee et al., 2020). The caveat to this finding is that family members were most likely to help with direct assistance and significantly less likely to help with financial support or support to make decisions. An implication of this finding is that support network members may need to diversify the help they provide to include financial support or decision-making so the onus of those tasks does not fall onto siblings.

Third, paid workers and other individuals often comprise the support network of individuals with IDD. This finding points to the need to consider integrated supports—both natural, unpaid supporters as well as paid supporters in the context of caregiving. Adults with IDD receive a large portion of their daily support through informal supports (i.e., not paid services, Sanderson et al., 2017). Informal, or natural, support can be provided by individuals associated with IDD such as parents, siblings, friends, and neighbors, as well as community resources, colleagues, and local members of the community (Bigby, 2008). Informal supports can not only relieve caregiving burden, but also enhance a person's quality of life (Cooley, 1994). Further, informal supports can be individualized, flexible, and promote self-determination (Sanderson et al., 2019). That being said, informal supports cannot replace formal services. It is critical for individuals with IDD to have integrated supports—the combination of formal and informal services. To that end, it is essential to explore and consider integrated supports to increase the size of the support network for individuals with IDD.

Relatedly, more research is needed about "other individuals" who comprise support networks. In our study, the most common "other individuals" included siblings-in-law and paid workers. Although less often studied, siblings-in-law engage in caregiving roles (Vanhoutteghem et al., 2013) and report mostly positive or mixed experiences with their brothers or sisters with IDD (Zemke et al., 2020). This study extends the literature by finding that siblings-in-law serve as important members of the support network. As a result, siblings-in-law should be considered in future planning interventions and decisions about caregiving. Regarding paid supporters, this finding aligns with extant literature suggesting that paid supporters play important roles in caregiving (Sanderson et al., 2017). It may be that paid supporters go above and beyond their duties in providing support. Altogether, future research needs to think beyond the “usual characters” (i.e., immediate family members) to other individuals who provide support.

Fourth, we can identify individuals with IDD prone to smaller support networks by certain characteristics. For example, specific disability types (i.e., autism and Down syndrome) were prone to smaller or greater support networks. This finding extends prior work by suggesting that the Down syndrome advantage may extend to support networks (Esbensen et al., 2010). However, more research is needed to understand why individuals with Down syndrome experience greater caregiving support. For example, it may be that there are greater supporters because individuals with Down syndrome (versus autism) report closer familial relationships (Hodap & Urbano, 2007). Alternatively, greater support networks for individuals with Down syndrome could be attributed to the greater resources across local, state, national, and international settings (Antonarakis et al., 2020).

Other characteristics may also contribute to the size of the support network. Consider maladaptive behaviors. Greater support networks for individuals with more maladaptive behaviors could be due to the need for a larger capacity to address and manage behaviors (Neece & Baker, 2008). Similarly, the larger networks for individuals with less functional abilities could be due to their need for more intensive, direct support (Lee et al., 2019). Even though individuals with greater maladaptive behaviors and fewer functional abilities may need larger support networks, this may be hard to attain given the current fiscal climate and shortage of trained providers (Owen et al., 2015). More research is needed to understand how individuals with IDD with more maladaptive behaviors and/or support needs develop larger support networks. By identifying how such networks are developed, such strategies can be replicated for other individuals with IDD with smaller networks.

Limitations

While there were many strengths to this study, there are also some limitations. First, we relied on cross-sectional data. Thus, we cannot determine causality. In addition, we relied on a convenience sample which was primarily recruited through sibling networks and disability organizations. The generalizability of the findings may be limited to siblings connected to the disability community. Perhaps relatedly, the sample was relatively White, female, and well-educated further limiting the generalizability of the results. Future research should focus on recruiting more diverse samples by utilizing personalized recruitment. While limited financial resources prevented the survey from being translated in other languages in this study, future research should be conducted in multiple languages to recruit a linguistically diverse sample. Further, future research may include more culturally responsive measures including cultural brokers or interviews to elicit feedback from more diverse samples. Finally, the findings are based on the self-report of the sibling of the individual with IDD. Other family members (e.g., the individual with IDD and their parents) may have different perspectives on network members.

Directions for Future Research

Longitudinal research is needed to understand the development of support networks over time. Among the general population, social networks ebb and flow over time (Uddin et al., 2016). Without longitudinal research, it is difficult to discern whether support networks also change over time. Longitudinal data can also shed light on whether support networks grow or shrink in relation to certain life events (e.g., a parent dying, a sibling moving away). Further, future research should consider the impact of the support network not only on the individual with

IDD but also on parents and siblings. Indeed, the size and quality of the support network may impact the experiences of parent and sibling caregivers. By understanding how support networks change over time and identifying when support networks may be large or small, we can develop interventions to be available at the appropriate times for individual with IDD.

Qualitative and mixed methods research is also needed to identify how transition and, more broadly, future planning may relate to support networks. Per person-family interdependent planning (Kim & Turnbull, 2004), decisions made about the future rely not only on the involvement of the individual with IDD but also caregivers, including family members. Such decisions are often made in the context of school-based transition planning or future planning. Qualitative research should examine the extent to which the support network is identifying and included in these decisions. For example, at transition planning meetings, to what extent are other support network members attending the meeting? In future planning interventions, to what extent are other support network members involved in decision-making? To that end, mixed methods research could inform how the efficacy of future planning interventions differs (or not) in relation to the support network size as well as elucidate the reasons why certain caregiving members are more or less interested in future planning. Research is needed to better understand the relation and involvement of support network members in planning practices.

Implications for Practice and Policy

Practitioners should try to help enlarge the circles of support around siblings of individuals with IDD as well as their brothers and sisters with IDD. By helping siblings identify peer support as well as their brothers and sisters have larger support networks, both can receive the needed social support to address their unique needs. Regarding siblings, practitioners may consider referring siblings to the Sibling Leadership Network or The Arc’s Sibling Council. In this way, siblings can meet other siblings and, correspondingly, enlarge their support network. For individuals with IDD, practitioners may help families identify other supporters including those in the community, paid supporters, or other family members.

Further, practitioners may reflect on whether they themselves are members of support networks for individuals with IDD. They may consider their roles in relation to the individuals with IDD they serve and their families. To this end, practitioners may consider whether they want to be a part of the support networks and wherein their paid work ends and their assistance begins. Given that paid workers often spend significant time with an individual with IDD, they may be trusted members of their decision-making teams. Recognizing the importance of paid care workers, it is critical to invest in policies to strengthen our care infrastructure. National efforts such as the Better Care, Better Jobs Act offer incentives to improve the recruitment, retention, payment, and training for direct care providers. Our study underscores the important roles of paid workers and the need for more supports to help ensure paid workers are supported themselves so they can continue to support individuals with IDD.

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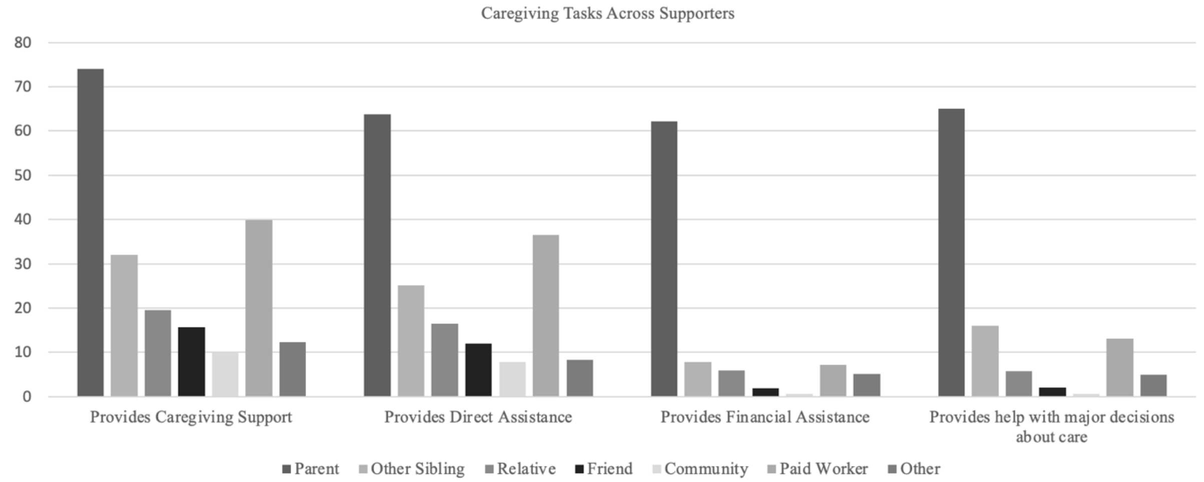

Figure 1. Caregiving Tasks Across Supporters

Table 1.

Participant Demographics (*N* = 601)

Characteristic	% (*n*)
Gender: Female	88.35% (531)
Marital Status: Married	46.09% (277)
Race/Ethnicity*	
White	87.69% (527)
Hispanic/Latino	5.82% (35)
Black/African American	3.66% (22)
Asian/Pacific Islander	4.49% (27)
Other	2.50% (15)
Educational Background	
Some high school	1.0% (6)
High school graduate	4.49% (27)
Some college	16.37% (106)
College graduate	31.78% (191)
Some graduate school	10.82% (65)
Graduate school graduate	34.28% (206)
Annual Household Income	
Less than $20,000	11.31% (68)
Between $20-40,000	13.97% (84)
Between $40-60,000	17.80% (107)
Between $60-80,000	17.14% (103)
Between $80-100,000	12.48% (75)
More than $100,000	24.96% (150)

Table 2.

Correlations Among the Variables

	1	2	3	4	5	6	7
1- Support network	---	---	---	---	---	---	---
2-Functional abilities	-.03	---	---	---	---	---	---
3-Maladaptive behaviors	.05	.18**	---	---	---	---	---
4- Parent caregiving ability	.22**	.35**	.02	---	---	---	---
5-Disability Insiderness	.18**	.02	.02	.05	---	---	---
6-Down syndrome	.17**	-.12**	-.17**	.12**	.04	---	---
7-Autism	-.10*	-.05	.39**	.18**	-.01	-.29**	---
8-Racial Background	.08	-.07	.01	-.01	.01	.09*	-.09*

*refers to $p < .05$, ** refers to $p < .01$

Table 3.

Comparisons of Supporters

	Self	Parent	Other sibling	Relative	Friend	Community	Paid worker	Other
Provides caregiving support	61.73% (371) Siblings< parents** Siblings> other siblings** Siblings> relatives** Siblings> Friends** Siblings> Community** Siblings>paid workers Siblings> other**	74.04% (445) Parents> siblings** Parents> other siblings** Parents> relatives** Parents> friends** Parents> community** Parents> paid workers** Parents> other**	31.95% (192) Other siblings> relatives** Other siblings> friends** Other siblings> community** Other siblings> other** Other siblings< paid worker*	19.47% (117) Relatives> Friends** Relatives> Community** Relatives> others* Relatives< paid worker**	15.64% (94) Friends> community** Friends< Paid worker **	9.82% (59) Community < paid workers**	39.82% (239) Paid worker> Other**	12.31% (74)
Provides direct assistance	---	63.72% (383) Parents> Other siblings** Parents> Relatives** Parents> Friends** Parents>	25.12% (151) Other siblings> Relatives** Other siblings> Friends** Other siblings> community**	16.47% (99) Relatives> Friends* Relatives> Community** Relatives< Paid workers** Relatives>	11.98% (72) Friends> Community* Friends<Paid workers** Friends> Others*	7.82% (47) Community <Paid workers** Community	36.44% (219) Paid workers> Others**	8.32% (50)

		Community** Parents> Paid worker**	Other siblings<paid workers Other siblings>other**	Others**				
Provides financial assistance	---	62.22% (374) Parents> Other siblings** Parents> Relatives** Parents> Community** Parents>Paid worker** Parents> Others**	7.82% (47) Other sibling> Friends** Other sibling> Community**	5.82% (35) Relatives> Friends** Relatives> Community**	1.83% (11) Friends<Paid workers** Friends> Others*	.67% (4) Community <Paid workers** Community < Others**	7.15% (43)	5.16% (31)
Provides help with major decisions about care	---	65.06% (391) Parents> Other siblings** Parents> Relatives** Parents> Community** Parents>Paid worker** Parents> Others**	15.97% (96) Other sibling> relative** Other sibling> friends** Other sibling> Community** Other sibling> Others**	5.66% (34) Relatives> Friends** Relatives> Community** Relatives< Paid worker**	1.99% (12) Friends< Paid worker** Friends> Others*	.67% (4) Community <Paid workers** Community < Others**	13.14% (79) Paid workers> others**	4.99% (30)

Table 4.

Open-Coding of “Other” Responses for Support Network Members

“Other” Responses	% (*n*)
Sibling-in-law	31.15% (38)
Paid worker	31.14% (38)
None or no one	9.84% (12)
Niece or nephew	9.02% (11)
Other sibling	6.56% (8)
Person with a disability’s significant other	5.74% (7)
Parent or guardian	3.28% (4)
Other	1.64% (2)
Friends	0.82% (1)
N/A	0.82% (1)

Table 5.

Differences in Caregiving Tasks within Support Network Roles

	Provides direct assistance	Provides financial assistance	Provides help with major decisions about care	Differences within Support Network Role	Follow-up analyses
Parent	63.73% (383)	62.22% (374)	65.06% (391)	X^2 = 10.09**	Help > Financial*
Other sibling	25.12% (151)	7.82% (47)	15.97% (96)	X^2 = 126.89**	Finance < Direct** Finance < Help** Direct > Help**
Relative	16.47% (99)	5.82% (35)	5.66% (34)	X^2 = 100.27**	Direct > Financial** Direct > Help**
Friend	11.98% (72)	1.83% (11)	1.99% (12)	X^2 = 101.69**	Direct > Financial** Direct > Help**
Community	7.82% (47)	6.66% (4)	6.66% (4)	X^2 = 82.18**	Direct > Financial** Direct > Help**
Paid worker	36.44% (219)	7.15% (43)	13.14% (79)	X^2 = 278.88**	Direct > Financial** Direct > Help** Financial < Help**
Other	8.32% (50)	5.16% (31)	4.99% (30)	X^2 = 24.58**	Direct > Financial ** Direct > Help**

Table 6.

Linear Regression for Support Networks

	B (*SE*)	Beta	*t*	*p*
Parent caregiving ability	.19 (.03)	.25	5.76	<.001
Functional abilities	.02 (.01)	.09	2.16	.03
Disability insiderness	.02 (.01)	.17	3.95	<.001
Maladaptive behavior	.02 (.01)	.17	3.84	<.001
Down syndrome	.28 (.14)	.09	.04	.01
Autism	-.45 (.14)	-.15	-3.19	.002
Racial background	.32 (.18)	.08	1.80	.07