# American Journal on Intellectual and Developmental Disabilities Understanding Natural Supports in Diverse Adults with Intellectual and Developmental Disabilities

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NATURAL SUPPORTS 1

# Abstract

Although natural supports benefit individuals with intellectual and developmental disabilities (IDD), little is known about natural support provided within specific life domains or how race/ethnicity or support from professionals impacts the extent of natural support one receives. In this study, 518 parents of adults with IDD responded to a national survey about natural supports, including who provides support, the number of supporters, and variables that predict natural supports. Family most often provided support, although professionals and family friends were frequent supporters in several domains. Natural support was most extensive in health, least extensive in employment and housing. Individuals with IDD who regularly participated in daytime activities and/or identified as Black had more extensive natural support. Implications are discussed.

*Keywords:* natural support; intellectual and developmental disabilities; families; ethnic/racial differences; professional support

Understanding Natural Supports in Diverse Adults with Intellectual and Developmental

Disabilities Across Life Domains

Every day, people turn to others for help with tasks both small and large. Unpaid assistance from people in one's social network is referred to as natural, or informal, supports (Duggan & Linehan, 2013). Although natural supports are not unique to the disability community and having more extensive natural support likely benefits adults with intellectual and developmental disabilities (IDD, Friedman, 2021; Reynolds et al., 2018), only a few studies have examined the natural support received by persons with a disability. The sense, however, is that many adults experience few natural supports. In one study assessing the helpfulness of 13 natural supporters for 212 adults with IDD and their families, most potential supporters did not provide any natural support (Robinson et al., 2016). More generally, the issue of natural support remains underexplored for the entire population of adults with IDD.

Specifically, natural supports for adults with IDD remain underexamined in three main ways. A first issue pertains to who these supporters are. Although natural supports can come from anyone in a person's social network (Bigby, 2008), natural supporters have generally been thought to include family members, friends, co-workers, and community members (e.g., neighbors, members of faith communities). Most studies identify family members, especially parents (Williamson & Perkins, 2014) and siblings (Hall & Rossetti, 2018), as the primary natural supporters. But there may be some overlap between formal and informal supports, as some paid professionals might provide assistance to adults with IDD that goes above and beyond their paid duties. In one survey study, for example, parent respondents were specifically asked *not* to list those individuals paid to provide supports as natural supporters. Nevertheless, many respondents listed caregivers, group home staff, job coaches, and other paid professionals as

people who provided natural supports (Sanderson et al., 2017). Yet the ways in which paid professionals serve as natural supporters remains unknown. The concept of "integrated supports" (Reynolds et al., 2019)—combining natural and paid supporters—acknowledges this potential overlap of formal and informal supports.

A second issue concerns areas of natural support. The need for natural supports can arise in many life domains: employment, housing, and recreation (Sanderson et al., 2019).

Employment might include researching, finding, and maintaining paid and unpaid work and housing involves helping with living arrangements, whether it be housing the person or helping them find a suitable place to live. Recreation might refer to participating in leisure activities, such as playing a game or going on enjoyable outings. But other important life domains also exist, such as healthcare and community integration (Reynolds et al., 2019). Thus, it seems critical to examine natural supports related to such healthcare needs as managing prescription medication, doctor's appointments, and/or health issues. Natural supports also matter for community integration, which includes participating in activities and events within the community. To attain a more comprehensive understanding of the needs of adults with IDD, we need to examine natural supports across multiple domains.

A third under-researched area concerns research samples. To date, few existing studies examine sizeable sub-samples of Black, Latinx/Hispanic, or families from lower socioeconomic status, even as such families are over-represented among U.S. adults with IDD (U.S. Census Bureau, 2021). We also suspect that natural-support differences may exist compared to predominantly White, middle-class study samples. For instance, generally speaking, individuals who identify as Black often place a high value on family as a social support network, regularly receiving and providing support to nuclear and extended family members (Cross et al., 2018).

Similarly, given the widespread adoption of "familism"—or strong feelings of attachment, loyalty, and reciprocity toward one's family (Magaña & Smith, 2006)—Latinx/Hispanic families may have greater numbers of natural supporters among immediate or extended family members. Similarly, families with greater household incomes and more people living in the home should have greater numbers of natural supports, given the increased fiscal and social capital available in the family (Yosso, 2005). Despite such likely differences, few studies include large enough samples of families who are Black, Hispanic, or low-income to examine such hypotheses.

This study, then, examined natural supports through the use of a large-scale, national survey of parents of adults with IDD. Building on previous research, we made special efforts to recruit a more diverse group of participants, directly assess the natural support provided by professionals who work with the individual, and explore additional domains of support. By examining factors associated with increased natural supports, we identify ways to improve social support networks and provide targeted interventions to those at-risk of having inadequate support. We addressed the following research questions: (1) Who provides natural support to adults with IDD and how much support do they provide? (2) Do the number of natural supporters and/or extent of natural support differ by life domain? and (3) What factors predict an increased amount of natural support received within each life domain? Our hypotheses were grounded in the belief that, while all individuals with IDD benefit from natural supports, those with certain characteristics are more likely to receive natural support. We hypothesized that characteristics of the adult with IDD, the family, and the natural support network would significantly relate to the number and extent of natural support in each life domain. Specifically, we hypothesized that, given the fiscal and social capital available in the family (Yosso, 2005), families with greater household incomes and more people living in the home would positively correlate with the

number of natural supports. We also hypothesized that Hispanic/Latinx families would have more natural supports given familism (Magaña & Smith, 2006). With respect to characteristics of the adults with IDD, we hypothesized that older age would positively correlate with natural supports, as older individuals may have greater needs as they age, but also have more time to develop social networks and cultivate relationships. We also hypothesized that individuals in better health, without (versus with) ID, engaging in daytime activities, and having less problem behaviors would be significantly more likely to have more natural supporters, as individuals with less support needs often have larger social networks (Herbert et al., 2020). Given that parents are often the gatekeepers and service coordinators for their offspring with IDD (Taylor et al., 2020), we hypothesized that parent involvement in creating a natural support network would correlate with more extensive natural supports in life domains.

#### Method

# **Participants**

To take part in this study, participants were required to be the parent of an adult with IDD who was 18 years or older. A total of 606 parents responded to the online survey. After removing participants who responded to less than 25% of questions (n = 88), we were left with a final sample of 518 respondents.

Parent respondents were 70% mothers. They ranged in age from 37-80 years (M = 47.97, SD = 3.55), resided across 41 U.S. states plus D.C., and had a median family income of \$50,000-\$59,999 (national median = \$70, 784 [U.S. Census Bureau, 2021]). In terms of race and ethnicity, participants in our study closely matched U.S. demographics (U.S. Census Bureau, 2021); over 10% of our sample were Black/African American and Latinx/Hispanic, respectively. Further, 8.9% (n = 46) completed the survey's Spanish-language version and over 15% either did

not graduate high school or their highest education was a high school diploma/GED. Adult offspring with IDD were primarily male and ranged in age from 18-60 years (M = 23.51, SD = 7.69). Common disabilities included ID, autism spectrum disorder (ASD), and emotional disturbance (more than one disability could be identified). See Table 1.

#### **Procedures**

The survey was developed via an iterative process, using concepts from the natural supports literature (e.g., Reynolds et al., 2018; Sanderson et al., 2017; Sanderson et al., 2019). Three parents of adults with IDD provided feedback, after which we revised the survey. We then submitted the protocol to the university institutional review board and, upon receiving approval, the survey was published online using Qualtrics from December 2021 through May 2022. The survey took approximately 30 minutes to complete and featured an incentive wherein 50 participants were randomly selected to receive a \$25 Amazon gift card. Upon completing the survey, participants were given access to an information and resource list for caregivers of individuals with IDD curated by the first author. All data were collected in Qualtrics, then transferred to SPSS (version 28.0) for analyses.

# Recruitment

To attain a large and diverse sample, we reached out to multiple disability and parent support organizations across the U.S., asking them to share our study with their clients.

Organizations and groups included: 21 California Regional Centers; 56 state (and territory)

Developmental Disability Councils; 68 University Centers for Excellence in Developmental Disabilities; 126 national IDD organizations listed by Wrightslaw Yellow Pages for Kids; 309 inclusive postsecondary education programs; and 1,003 national, state, and local chapters of

disability organizations (i.e., The Arc, EasterSeals, Fragile X Foundation, National Down Syndrome Society, United Cerebral Palsy, TASH).

To foster heightened representation from diverse respondents, we also approached multiple service organizations, many of which especially work with diverse groups. Thus, in addition to the above organizations, we recruited through 101 Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) and 76 Protection and Advocacy (P&A) Centers and Client Assistance Programs (CAPs). We also emailed *and* called an additional 97 parent groups across the U.S. who specialize in working with families from diverse racial, ethnic, linguistic, and socioeconomic backgrounds.

# Survey

The survey consisted of four sections, asking questions about (1) the parent respondent; (2) their offspring with IDD; (3) natural supports; and (4) the parent's social support network (e.g., who the parent can turn to for support, satisfaction with social support network). Most responses were on a Likert-type scale. Branching logic was used throughout the survey.

# Outcome Variables

Our primary outcome variables were (a) the natural supporters helping adults with IDD and (b) the extent of natural support received within each of five life domains (i.e., employment, housing, recreation, health, and community access). Respondents were first told that "Natural supports are **unpaid help or assistance**" (underlined and bolded in the survey). We then asked respondents to rate the support that each of the following seven potential natural supporters provided: parents, siblings, other family members, family friends, faith community, service providers, and others. "Others" was a category meant to capture any other potential natural supporters beyond the listed options in each life domain. Each supporter was rated on the amount

of natural support they provide in each domain: (0) Not at all; (1) A little bit; (2) A lot. Respondents were also asked to rate the total amount of support their son/daughter with IDD received in each life domain on a 5-point scale, from (0) No help to (4) A lot of help. Examples of natural supports were provided for each domain.

# Independent Variables

Independent variables included characteristics of the parent respondent, their adult offspring with IDD, and their offspring's natural support network. Parent-family characteristics included: annual household income ( $I = \langle \$20,000 \text{ to } 10 = \rangle \$100,000$ ), physical health (I = poor to 5 = excellent), the total number of people living in their home (I = one, 2 = two, 3 = three or more), and race/ethnicity (I = Black or African American; 2 = Non-Hispanic White; 3 = Asian American or Pacific Islander; 4 = Hispanic or Latinx). Familism was measured using the 3-item "Perceived Support from Family" subscale ( $\alpha = .70$ ), which is part of the larger, 13-item Familism Scale (Sabogal et al., 1987). This subscale measures a person's "perception of family members as reliable providers of help and support" (Sabogal et al., 1987, p. 401) by asking respondents to rate their agreement with the following statements on a 5-point scale (I = very much in disagreement to S = very much in agreement): (1) "When someone has problems s/he can count on the help of relatives;" (2) "When one has problems, one can count on the help of relatives;" and (3) "One can count on help from his/her relatives to solve most problems."

Characteristics of the individual with IDD included: age, health (1 = poor to 5 = excellent), if they lived with their parents (0 = no, 1 = yes); whether the individual was identified as having ID (0 = no, 1 = yes) and/or ASD (0 = no, 1 = yes); whether the individual regularly participated in any education, work, and/or volunteer activities (0 = no, 1 = yes); and maladaptive behavior. Disability diagnoses were based on parent report. Maladaptive behavior

was measured using the General Maladaptive Index of the Scales of Independent Behavior-Revised (SIB-R;  $\alpha$  = .82; Bruininks et al., 1996), wherein respondents report on the frequency and severity of eight maladaptive behaviors; lower scores indicate more serious behavior.

Characteristics of the adult with IDD's natural support network included if the parent organized their child's natural support network (i.e., found unpaid helpers to assist their child;  $\theta = no$ , t = total number of formal disability services (e.g., Vocational Rehabilitation, Social Security Disability Insurance, Supplemental Security Income) the individual was receiving (from 0-9), and the extent of natural support provided by various supporters within each domain (i.e., parent[s], sibling[s], other family members, family friends, service providers, and faith community) from 0 (totatat) to 2 (totat).

# **Data Analyses**

First, we examined the amount of help provided by each type of natural supporter within each life domain by calculating the percentage of supporters who provided each level of support (i.e., "not at all", "a little bit", and "a lot") in each life domain. For example, we calculated the percentage of siblings who provided "no support", "a little bit of support", and "a lot of support" in employment, housing, recreation, healthcare, and community access, respectively. We then categorized the natural supporters into two categories for each life domain: those who did not provide support (0) and those who provided support (scores of 1, "a little" and 2, "a lot"). We calculated the percentage of adults with IDD receiving some level of help from each type of natural supporter in each of the five life domains. We then summed the number of natural supporters providing help in each life domain using these binary categories. Finally, we conducted a one-way repeated measures ANOVA to compare the mean number of supporters across life domains. Next, to examine the extent of natural support received, we calculated the

mean and standard deviation in each life domain. We then conducted a one-way repeated measures ANOVA to compare the extent of support across the five domains.

We conducted a series of regression analyses to determine factors that predict the extent of natural support received within each life domain. Independent variables (above) were the same for each domain and included characteristics of the parent respondent, their adult offspring with IDD, and their child's natural support network. Dummy variables were created for the race/ethnicity categories to be included in the regression analyses (e.g., Black = 1, non-Black = 0; Hispanic = 1, non-Hispanic = 0; etc.). Notably, the White race/ethnicity variable was highly correlated with two other variables (Black, r = -.60, and Hispanic, r = -.53). If each of the race/ethnicity groups were included, there would have been redundancy in the regression model, creating an issue with multicollinearity. Accordingly, the White race/ethnicity variable was excluded from the model, allowing it to be the reference group for the other race/ethnicity variables. To determine differences in the extent of natural support received by those from various racial/ethnic backgrounds, we conducted a series of one-way ANOVAs (see Table 1 in supplemental files). We also conducted chi-square analyses to better understand outcomes related to increased natural support. Specifically, we performed follow-up analyses to compare the number of (a) Black vs. non-Black respondents and (b) respondents whose offspring participated in regular daily activities vs. those without regular activities who reported high levels of natural support (i.e., scores of 4, "moderate amount of help" or 5, "a lot of help") for their adult offspring with IDD in each life domain.

#### **Results**

**Roles of Natural Supporters Across Life Domains** 

Parents were the top natural supporters, providing "a lot" of support for 41.4% of the sample in employment to 70.8% in healthcare. Siblings were also among the top natural supporters, providing "a lot" of support in several domains (i.e., second in recreation [35.7%], third in both employment [24.8%], and community access [23.4%]). In two life domains each, service providers (employment [25.4%] and health [29.5%]) and other family members (housing [29.3%] and community access [28.3%]) had the second highest percentage of supporters, providing a "lot of" support. "Other" supporters placed last in every life domain. See Table 2.

Of the seven types of potential natural supporters, parents were the most likely to provide some level of support in each of the five domains. Service providers ranked second as the most likely natural supporter in three domains (employment, housing, health) and third in two domains (recreation and community access). Notably, in the employment and housing domains, family friends ranked third in providing some level of natural support – placing higher than siblings in both domains. See Figure 1 for an overview of natural supporters by life domain.

Respondents reported the lowest number of natural supporters in housing and the most in recreation and employment. A repeated measures ANOVA (with Greenhouse-Geisser correction) revealed differences in the number of natural supporters between life domains, F (3.35, 1286.23) = 44.478, p < .001. With the exception of healthcare and community access (p > .05), post-hoc analysis with a Bonferroni adjustment revealed significant differences between the number of natural supporters in all life domains (pairwise all p 's < .001). See Table 3.

# **Amounts of Natural Support Across Life Domains**

Almost all (95.1%) adults with IDD received some natural support in a least one life domain, with 55.6% (n = 259) receiving support in all five. The most extensive support was reported in the health domain, while employment and housing showed the least extensive

support, (ANOVA with Greenhouse-Geisser correction) F (3.32, 1542.29) = 47.86, p < .001. Post-hoc analyses revealed significant differences between the extent of natural support received in: employment or housing (both lower) and recreation, community access, and healthcare (higher); and healthcare over community access (all p 's < .001). Notably, many respondents reported their adult offspring with IDD received "no help" in housing (34.1%) and employment (28.9%). Conversely, only 14.9% of adults received "no help" in the health domain, with 24.7% participants reporting that their offspring received "a lot" of help in that domain. See Table 3.

Across the five domains, we also examined the connections between the number of supporters and the extent of help that was received. As Table 3 shows, the overall rankings of number of supporters and extent of support were in sync for the housing, recreation, and community access domains (e.g., housing was ranked  $2^{nd}$  for both number of supporters and extent of support), but not for the employment and health life domains (e.g., employment was ranked  $1^{st}$  in number of supporters, but  $4.5^{th}$  in extent of support received). Correlations between the number of supporters and extent of support within each life domain were much stronger in employment (r = .50) and housing (r = .48) than in recreation (r = .18), health (r = .16), or community (r = .25; all p's < .001).

# **Factors Predicting the Extent of Natural Support**

# **Employment**

The regression for employment was significant, F(22, 355) = 13.44, p < .001, accounting for 47.0% of the variance. More extensive natural support was found when the individual was not diagnosed with ID, participated in regular activities, and received more help from parents, siblings, extended family members, and faith members. More extensive levels of natural support were also noted when there were more people living in the family home and when the respondent

was Black. Whereas only 20.6% of the non-Black adults with IDD received "high levels" (i.e., 4 or 5) of employment support, 69.7% of Black adults with IDD received high levels of support,  $\chi^2$  (1, N = 484) = 69.34, p < .0001. See Table 4.

# Housing

With 42.9% of the variance accounted for, the regression for the extent of natural support for housing was also significant, F(22, 361) = 11.59, p < .001. More extensive natural support in housing was noted when respondents were Black and adults with IDD received more help from their parent(s) and extended family members. More extensive housing support was also associated with the adult with IDD's physical health status, with individuals in better health receiving more support. Differences were especially noteworthy when parent respondents were Black, with high levels of natural support in housing occurring three times more often in Black (72.1%) vs. non-Black (24.0%) adults with IDD,  $\chi^2(1, N = 481) = 63.38$ , p < .0001.

# Recreation

The regression for natural support in recreation was significant, F(22, 364) = 4.58, p < .001, and accounted for 22.7% of variance. More extensive natural support was found when the parent respondent was Black or AAPI, when parents and siblings provided more recreation support, and when the adult with IDD was in better physical health and regularly participated in any education, work, or volunteer activities.

#### Healthcare

More extensive natural support in health care occurred when the parent(s) and extended family members provided more healthcare support, the individual with IDD regularly participated in any education, work, or volunteer activities and more people lived in the family

home. The regression was significant, F(22, 362) = 3.13, p < .001, accounting for 16.9% of the variance.

# Community Access

The regression for community access was significant, F(22, 360) = 5.09, p < .001, accounting for 26.1% of the variance. More extensive natural support was noted when the parent(s), siblings, and extended family members provided more community support, and when the adult with IDD regularly participated in any education, work, or volunteer activities. Of those adults with IDD who regularly participated in activities, 41.4% showed high levels of community access, compared to 25.0% of adults who did not participate in any regular activities,  $\chi^2(1, N = 480) = 7.88$ , p = .005.

#### **Discussion**

Building on preliminary studies of natural supports, this study examined responses from a national survey of participants who closely match U.S. demographics in terms of race and ethnicity (U.S. Census Bureau, 2021). Asking about different potential supporters—including professionals working with adults with IDD—this study also examined support in multiple life domains. Our study thus provides a fuller picture of who provides natural support, how much support they are providing, and variables associated with the amount of natural support received in five major life domains. Our study had three main findings.

Our first finding identified *who* provides natural support. Similar to prior research (e.g., Bigby, 1997; Linblad, et al., 2007; Sanderson et al., 2017), parents in our study generally provided the highest levels of natural support in every life domain. Siblings and other family members were also key natural supporters. While siblings are commonly acknowledged as critical members of the support network of adults with IDD (Burke et al., 2021; Hall & Rossetti,

2018; Sanderson et al., 2017), extended family members are not. This finding may, compared to past studies, relate to having a more racially and ethnically representative sample. In many cultures, individuals rely on extended family members to offer guidance in decision-making and provide caregiving support (Zhang & Bennet, 2013).

Equally intriguing was the role of disability service providers. Service providers ranked as the second most likely natural supporter in three life domains—employment, housing, health—and third in the remaining two (recreation, community access). Given that our study focused on natural supports—and service providers are not generally considered natural supporters (Bigby, 2008)—this finding may appear surprising, but other studies have noted this phenomenon. For instance, Sanderson et al. (2017) found that non-family members were frequently identified as natural supporters and more than 50% of non-family members were paid people (i.e., service providers). Such findings call into question any straightforward distinction between natural and formal supporters. Due to the nature of their work, service providers can often become deeply involved in their clients' lives. In some cases, service providers may offer supports that are not included in their official job description (Duggan & Linehan, 2013), going beyond their jobs to provide supports more akin to a friend or family member.

A second finding concerned the varying number of supporters and amounts of natural support received in each life domain. The numbers of people providing natural support differed across life domains, with employment highest and housing fewest. Similarly, the amounts of support also differed by domain, with the most extensive natural support reported in the healthcare domain and the least extensive natural support in employment and housing.

These findings may point to the differing needs for support in each life domain amongst adults with IDD in our study. For instance, many adults with IDD have co-occurring health

issues (Ptomey et al., 2020). As such, these individuals may require help navigating medical appointments, following doctors' orders, and managing prescription medications. Less extensive natural support in housing may occur because most adults with IDD live with family (over 80% in this sample; Larson et al., 2020); these adults may not require help with finding or securing suitable living arrangements at the moment.

Although consistent with prior studies (e.g., Sanderson et al., 2019), low amounts of natural support in employment and housing are still concerning. Though some adults may not require housing support at the moment, living arrangements change, especially when parents become older and less able to care for their adult offspring with IDD (Lee et al., 2021). It therefore seems essential that adults with IDD have in place appropriate supports and plans to deal with this life change. Alarming as well were the low amounts of employment support, as employment rates for adults with disabilities continue to lag behind their nondisabled peers (U.S. Department of Labor, 2022).

It is also important to consider connections (or lack thereof) between the numbers and amounts of natural supports within life domains. Looking at overall rankings across the five domains, the employment domain averaged the highest numbers of natural supporters, but the least amount of support. Conversely, housing was lowest on both the mean number of supporters and the amount of support. Within each group separately, both employment and housing showed close connections between the numbers and amounts of natural supports (ties were looser in the other three life domains). At least for certain life domains, it is the *quality* of support, rather than the quantity of supporters, that actually matters.

Finally, our third finding identified the predictors of increased natural support in the five life domains. Regular participation in educational, work, and/or volunteer activities strongly

predicted having more extensive natural supports in four of the five domains. In a national, large-scale study of approximately 800 adults with IDD, Taylor and Hodapp (2012) found that nearly 13% of adults with IDD were without daytime activities. Compared to adults with IDD who participated in regular activities, these adults had more emotional—behavioral and health problems, were more underserved by the formal service system, had weaker relationships with siblings, and had parents who were less able to provide adequate care. Clearly, participating in regular daily activities seems associated with many side benefits for adults with IDD, including accessing more extensive natural supports.

An additional, important predictor of increased natural support involved being a member of a Black family. Compared to other families, Black families showed more extensive natural supports in three of five life domains: employment, housing, and recreation. Black families have many strengths; for instance, individuals who identify as Black often place a high value on family as a social support network and regularly receive and provide support to nuclear and extended family members (Cross et al., 2018). Indeed, much higher percentages of Black children (57%) spend some time in extended family households than do White (20%) or Hispanic (35%) children (Cross, 2018). Given that Black families have also historically been underserved by helping professions, including disability services (Hassiotis, 2020), it follows that Black families may take on greater responsibilities caring for family members with disabilities.

# Implications for Policy, Practice, and Research

These findings have major implications for the disability field. In line with existing research (e.g., Linblad et al., 2007), our results indicate that family members, including parents, siblings, and extended family, constitute the primary natural supporters in the lives of adults with

IDD. To ensure adults with IDD have continued access to needed natural supports, policymakers and disability service providers must develop supports that meet family members' needs. This study is the second large-scale study (along with Sanderson et al., 2019) to implicate employment and housing as two areas in which people with disabilities have the least amounts of natural support. Considering that most adults with IDD are not receiving formal supports (Larson et al., 2020), many people likely have little help in finding, obtaining, or maintaining work and housing. These two areas seem ripe for increased attention and resources.

Given that service providers were identified as a top provider of natural supports, policymakers should further examine integrated supports for adults with IDD (Duggan & Linehan, 2013). Rather than treating natural and formal supports as separate entities, steps should be taken to develop a more comprehensive approach to helping adults with IDD, one that better equips "non-professionals" to meet the adult's daily needs (Sanderson et al., 2020). Ensuring all adults with IDD have options to successfully participate in meaningful activities should be a primary focus for policymakers.

These findings also highlight areas of needed research. Why, for example, do individuals have the least amounts of support in the employment and housing domains? Qualitative research may offer the best approach to obtain a rich description of individual and family needs in these areas. Second, what is it about regular activities, be these work, school, or volunteer, that fosters increased natural supports in almost every area? Third, given this study's relatively large Hispanic sample (n = 57), why were no findings specific to the Hispanic sub-group? Fourth, future research should focus on natural supports from the perspective of the individual with IDD. To gain an understanding of individuals' needs and to develop effective disability policy, it seems critical to hear directly from individuals with disabilities themselves (Rivas et al., 2021).

Finally, our findings indicate that, for certain life domains, it may be best to focus of the quality of natural support rather than the number of supporters. In the past, emphasis has been placed on expanding the size of social networks (e.g., Lippold & Burns, 2009); however, our findings suggest that a small, but competent, network may meet support needs better than a larger group (at least in certain life domains). But even here, questions abound. For instance, what makes someone a high-quality supporter in a specific life domain? Is it familiarity with specialized supports needed within that domain or intimate knowledge of the individual and their needs? Additionally, how do our parent-reported findings of high levels of natural support in healthcare align with findings of decreased healthcare access for adults with IDD (Krahn et al., 2006) or to the lower levels of preventive care for adults who live in their family homes (vs. other environments; Bershadsky et al., 2012)?

# Limitations

This study had limitations that must be noted. As an online survey, participants were limited to those who had access to the internet, which may have excluded individuals who live in rural areas and those from lower socioeconomic backgrounds. Next, because our survey featured parent respondents, findings only reflect their perspectives of natural supports. Parents may be more likely to know about support provided by themselves and by relatives (e.g., siblings) than by others. With self-report measures, participants have the potential to distort data by exaggerating responses (Gravetter & Forzano, 2019). The individual with IDD and/or other supporters may have offered different viewpoints. Additionally, we did not gather information about the extent of natural support received by adults with IDD whose parents are deceased. Further, participants were allowed to skip any survey item, which resulted in a varying number of responses to survey items. The findings reported in this manuscript are from complete case

analysis. However, missing data may have influenced our findings. To address this limitation, we conducted regression analyses with two sets of imputed data: (1) imputing the mode for 20 participants missing 1 item of the 16 item SIB-R scale (Harrell, 2015) and (2) imputing data using the multiple imputations technique (Li et al., 2015). Overall, findings from regression analyses conducted with these imputed data sets were similar to the findings reported in this manuscript (see Table 2 and Table 3 in supplemental materials). Finally, since the study was cross-sectional, we could not determine causal links between independent variables and the extent of natural support.

# **Conclusion**

Even with these limitations, however, this study provides valuable insight into the lives of adults with IDD. Deriving from a more racially and ethnically representative sample than prior studies, this study highlights the reality of natural supports for adults with IDD. In almost every life domain, parents, service providers, siblings and other family members were among the top natural supporters, while healthcare was the life domain with the highest and employment the lowest levels of natural supports. Finally, participation in some type of regular activity, being Black, and having greater help provided by family members were all among the strongest factors associated with more extensive natural supports across various life domains. By understanding how natural supports operate in the lives of adults with IDD, we can strengthen support networks to ensure everyone has access to the supports necessary to meet their daily needs.

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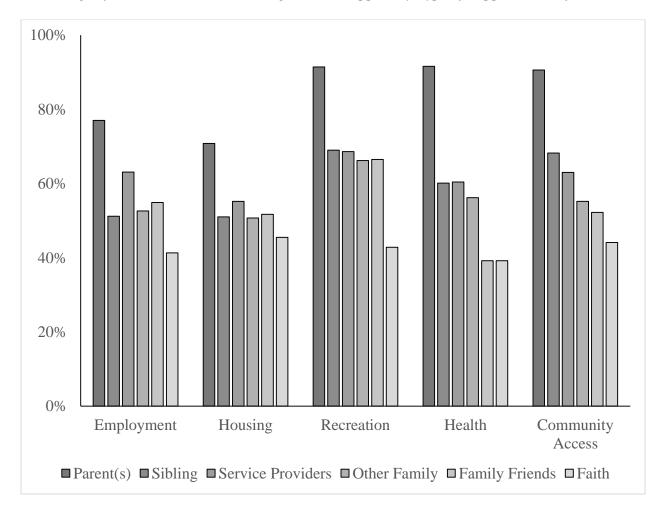
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Figure 1

Percentage of Adults with IDD Receiving Natural Support by Type of Supporter in Life Domains



**Table 1**Demographics of Parent Respondents and Their Adult Offspring with IDD

Characteristic		% (n)
Parent Respondents		
Gender	Female Male Other Gender Identity	69.0 (356) 30.6 (158) 0.4 (2)
Race/Ethnicity	White Black or African American Latinx/Hispanic Asian American and Pacific Islander (AAPI) Self-describe	68.3 (352) 13.6 (70) 11.1 (57) 6.4 (33) 0.6 (3)
Education	Some High School High School Diploma or GED Trade School or Vocational Training Some College, no degree Associate degree Bachelor's Degree Master's degree Professional or doctorate degree	4.9 (25) 10.5 (54) 2.1 (11) 26.7 (137) 11.1 (57) 26.3 (135) 15.0 (77) 3.5 (18)
Physical Health	Poor/Fair Good Very Good Excellent	27.5 (141) 49.1 (252) 18.7 (96) 4.7 (24)
Marital Status	Married/ Domestic Partner Single/Divorced/Widow	81.0 (417) 19.0 (98)
Household	<pre> \$20,000 \$20,001-\$50,000 \$50,001-\$80,000 \$80,001 - \$100,000 &gt; \$100,000</pre>	11.2 (54) 34.3 (166) 21.3 (103) 14.0 (68) 19.2 (93)
Years in U.S.A.	Born in U.S. 1-10 years 11-20 years Over 20 years	48.6 (236) 5.9 (29) 7.8 (38) 37.7 (183)
Adults with IDD Gender	Male Female Other gender identity	63.6 (316) 35.8 (178) 0.6 (3)

Disability	Intellectual Disability	47.9 (248)
·	Autism Spectrum Disorder	35.5 (184)
	Emotional Disorder	23.4 (121)
	Sensory Impairment (Hearing, Vision)	14.9 (77)
	Cerebral Palsy	15.1 (78)
	Down Syndrome	13.3 (69)
	Prader Willi syndrome	4.4 (23)
	Unspecified disability	4.2 (22)
	Fragile X syndrome	3.5 (18)
Physical Health	Poor	19.3 (98)
•	Fair	27.4 (139)
	Good	36.8 (187)
	Very Good	11.6 (59)
	Excellent	4.5 (23)
Maladaptive	Normal	37.0 (175)
(SIB-R GMI)	Marginal	16.5 (78)
	Moderate	17.1 (81)
	Serious	20.7 (98)
	Very Serious	8.7 (41)
Current Residence	With parents	70.1 (359)
	With siblings	11.5 (59)
	With unrelated persons (roommates or partner)	3.9 (20)
	Group home	8.2 (42)
	By themselves (with or without assistance)	3.7 (19)
	Other residential setting	2.5 (13)

*Note.* SIB-R GMI=Scales of Independent Behavior-Revised General Maladaptive Index

**Table 2**Amount of Natural Support Provided by Type of Supporter

	<u>E</u> 1	nployme	<u>ent</u>		Housing	7	F	Recreation	<u>on</u>		Health		Comi	nunity A	Access
	Not at all	A little bit	A lot	Not at all	A little bit	A lot	Not at all	A little bit	A lot	Not at all	A little bit	A lot	Not at all	A little bit	A lot
Parent	23.0	35.7	41.4	29.2	23.8	47.0	8.6	32.1	59.3	8.4	20.7	70.8	9.4	28.3	62.3
	(112)	(174)	(202)	(142)	(116)	(229)	(42)	(157)	(290)	(41)	(101)	(345)	(45)	(136)	(299)
Sibling	48.8	26.5	24.8	49.0	32.4	18.6	31.0	33.3	35.7	39.9	33.7	26.4	31.8	44.8	23.4
	(234)	(127)	(119)	(237)	(157)	(90)	(151)	(162)	(174)	(193)	(163)	(128)	(152)	(214)	(112)
Other Family Member	47.4 (225)	33.3 (158)	19.4 (92)	49.3 (239)	21.4 (104)	29.3 (143)	33.8 (164)	42.5 (206)	23.7 (115)	43.8 (210)	36.7 (176)	19.4 (93)	44.8 (215)	26.9 (129)	28.3 (136)
Family	45.1	33.2	21.7	48.3	31.6	20.0	33.5	37.3	29.2	47.4	25.1	27.6	47.8	31.7	20.5
Friends	(216)	(159)	(104)	(234)	(153)	(97)	(162)	(180)	(141)	(227)	(120)	(132)	(228)	(151)	(98)
Faith	58.7	24.7	16.6	54.5	22.1	23.3	57.2	25.1	17.7	60.8	21.7	17.5	55.9	26.5	17.6
	(280)	(118)	(79)	(264)	(107)	(113)	(278)	(122)	(86)	(292)	(104)	(84)	(266)	(126)	(84)
Service	36.9	37.3	25.4	44. 8	34.4	20.9	31.4	45.3	23.3	39.6	30.9	29.5	37.0	42.8	20.3
Provider	(179)	(183)	(123)	(219)	(168)	(102)	(154)	(222)	(114)	(192)	(150)	(143)	(177)	(205)	(97)
Other	76.5	14.3	9.2	76.8	13.7	9.4	71.9	16.0	12.1	75.6	14.3	10.1	76.0	15.2	8.8
	(365)	(68)	(44)	(375)	(67)	(46)	(350)	(78)	(59)	(366)	(69)	(49)	(364)	(73)	(42)

**Table 3** *Extent of Natural Support in Life Domains* 

Life Domain	No help (1)	A little help (2)	Some help (3)	Moderate amount of help (4)	A lot of help (5)	Extent of natural support received	Rank order of extent of natural support received	Number of natural supporters	Rank order of number of natural supporters
	% ( <i>n</i> )	% ( <i>n</i> )	% ( <i>n</i> )	% ( <i>n</i> )	% (n)	M(SD)		M(SD)	
Employment	28.9% (142)	20.6% (101)	23.0% (113)	17.9% (88)	9.6% (47)	2.59 (1.33)	4.5	4.31 (2.29)	1
Housing	34.1% (167)	16.5% (81)	18.2% (89)	19.0% (93)	12.2% (60)	2.59 (1.43)	4.5	3.49 (2.34)	5
Recreation	13.2% (65)	17.9% (88)	26.5% (130)	24.2% (119)	18.1% (89)	3.16 (1.29)	2	4.29 (1.77)	2
Health	14.9% (73)	13.1% (64)	24.7% (121)	22.7% (111)	24.7% (121)	3.29 (1.36)	1	3.81 (2.10)	4
Community Access	15.8% (76)	18.1% (87)	27.5% (132)	20.4% (98)	18.1% (87)	3.07 (1.32)	3	3.97 (1.88)	3

*Note.* Possible range for extent of natural support = 1-5; possible range for natural supporters = 0-7.

**Table 4**Regression Analyses for Extent of Natural Support in Each Life Domain

		Emplo	oyment			Но	ousing			Rec	reation			Hea	althcare		(	Commu	nity Acc	ess
Variables	β	SE	t	p	β	SE	t	p	β	SE	t	p	β	SE	t	p	β	SE	t	p
(Intercept)	.90	.45	2.01	.05	.69	.51	1.36	.18	.86	.51	1.68	.09	.70	.59	1.19	.24	.48	.51	0.93	.35
Parent																				
Black	.59	.20	2.90	.00	.81	.21	3.92	.00	.56	.23	2.43	.02	.37	.26	1.39	.17	.32	.23	1.41	.16
AAPI	.03	.26	0.13	.90	.20	.28	.72	.47	.76	.30	2.58	.01	.34	.33	1.04	.30	10	.29	-0.35	.73
Hispanic	06	.19	-0.31	.76	.13	.21	.63	.53	.06	.22	0.30	.77	.15	.24	0.63	.53	11	.22	-0.49	.63
Income	.03	.02	1.46	.15	00	.03	-0.13	.90	.01	.03	0.20	.84	.03	.03	0.95	.35	01	.03	-0.39	.70
Physical health	.06	.07	0.88	.38	03	.08	-0.22	.74	05	.08	-0.62	.53	03	.09	-0.33	.74	.00	.08	0.01	.99
People in family home	.18	.09	2.07	.04	13	.16	-0.78	.44	.13	.10	1.28	.20	.30	.12	2.58	.01	.15	.10	1.55	.12
Familism	.02	.03	.55	.58	05	.04	-1.21	.23	.02	.04	0.41	.68	.00	.04	0.09	.93	.00	.04	-0.04	.97
Adult with	IDD																			
Age	.01	.01	0.69	.49	.00	.01	0.169	.87	.01	.01	0.52	.60	.02	.01	1.52	.13	.01	.01	1.04	.30
Lives with parent	19	.15	-1.27	.21	13	.16	78	.44	11	.17	-0.69	.49	12	.19	-0.63	.53	.01	.17	0.07	.94
ID	27	.12	-0.22	.03	.06	.13	.48	.63	.14	.14	1.03	.31	02	.15	12	.91	.09	.14	0.65	.51
ASD	.07	.12	0.55	.58	03	.13	.48	.63	07	.13	-0.54	.59	.08	.15	0.52	.61	.00	.13	-0.03	.98
Physical health	.00	.06	0.05	.96	.15	.07	2.32	.02	.18	.07	2.69	.01	.03	.08	0.43	.67	.09	.07	1.29	.20
Has regular activities	40	.15	-2.70	.01	15	.16	-0.94	.35	59	.17	-3.50	<.001	41	.19	-2.18	.03	42	.17	-2.54	.01
SIB-R	.00	.00	0.21	.84	01	.01	-1.36	.18	01	.01	-0.94	.35	01	.01	-0.91	.36	01	.01	-1.31	.19

Support No	etwork																			
Formal services	09	.05	-1.75	.08	.03	.06	0.60	.55	.00	.06	0.01	.99	.01	.07	0.18	.86	.03	.06	0.45	.65
Parent organizes natural support	01	.156	-0.09	.93	.05	.17	0.27	.79	.21	.17	1.21	.23	.14	.19	0.73	.47	.18	.18	0.97	.33
Parent	.52	.08	6.40	.00	.51	.08	6.56	<.001	.43	.12	3.62	<.001	.46	.13	3.62	<.001	.54	.11	4.93	<.001
Sibling	.29	.09	3.36	.00	.14	.09	1.49	.14	.19	.09	2.10	.04	.14	.11	1.31	.19	.29	.10	3.05	.00
Other family member	.25	.10	2.53	.01	.53	.10	5.03	<.001	.08	.11	0.76	.45	.42	.13	3.33	<.001	.21	.10	2.06	.04
Family friend	.16	.10	1.63	.10	.10	.11	0.90	.37	.15	.10	1.52	.13	.02	.14	0.11	.91	.14	.10	1.32	.19
Faith community	.23	.10	2.30	.02	.13	.12	1.01	.31	.17	.10	1.78	.08	04	.12	-0.31	.76	.15	.10	1.52	.13
Service provider	06	.08	-0.75	.45	.15	.10	1.58	.12	04	.10	-0.42	.67	.09	.11	0.89	.38	.04	.10	0.42	.68

Supplemental Table 1

One-Way Analyses of Variance in Extent of Natural Support in Life Domains by Race/Ethnicity Categories

Extent of Natural Support in Life Domain	Blac	ek	Hisp	anic	AA	PI	Wł	nite	F	p	$\eta^2$
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>			
Employment	3.59	0.86	2.55	1.43	2.07	1.30	2.44	1.30	17.03	<.001	.10
Housing	3.57	0.95	2.43	1.43	2.81	1.79	2.38	1.39	14.89	<.001	.09
Recreation	3.65	0.91	2.96	1.41	3.41	1.65	3.07	1.27	4.61	.003	.03
Healthcare	3.75	0.85	3.33	1.37	3.69	1.57	3.15	1.41	4.64	.003	.03
Community	3.66	0.96	2.82	1.48	2.96	1.54	2.99	1.31	5.50	.001	.03

*Note.* AAPI = Asian American and Pacific Islander

Supplemental Table 2

Regression Analyses for Extent of Natural Support in Each Life Domain – Imputed SIB-R Data (Mode)

		Emp	loyment			Но	ousing			Rec	reation			Hea	althcare		C	Commu	nity Acc	ess
Variables	β	SE	t	p	β	SE	t	p	β	SE	t	p	β	SE	t	p	β	SE	t	p
(Intercept)	.81	.44	1.86	.06	.74	.49	1.50	.14	.80	.50	1.61	.11	.70	.57	1.22	.23	.35	.50	0.70	48
Parent																				
Black	.65	.20	3.27	.001	.81	.20	3.95	<.001	.57	.23	2.53	.01	.35	.26	1.24	.18	.36	.23	1.60	.11
AAPI	.04	.25	0.15	.88	.35	.28	1.26	.21	.82	.28	2.87	.00	.40	.32	1.28	.20	11	.29	-0.40	.69
Hispanic	.06	.19	0.30	.76	.19	.20	0.92	.35	.04	.21	0.20	.85	.14	.23	.58	.56	07	.21	-0.35	.73
Income	.03	.02	1.44	.15	01	.03	-0.22	.83	.00	.03	0.11	.92	.02	.03	0.68	.50	01	.03	-0.45	.65
Physical health	.07	.07	1.01	.31	.00	.08	0.00	.99	05	.08	-0.66	.51	02	.09	-0.21	.84	.01	.08	0.09	.93
People in family home	.16	.09	1.01	.31	.01	.10	0.06	.95	.13	.10	1.31	.19	.31	.12	2.72	.01	.17	.10	1.75	.08
Familism	.03	.03	0.82	.41	05	.04	-1.30	.19	.01	.04	0.30	.77	.00	.04	0.04	.97	.00	.04	-0.08	.94
Adult with	IDD																			
Age	.01	.01	0.64	.52	.00	.01	-0.04	.97	.01	.01	0.48	.63	.02	.01	1.34	.18	.01	.01	1.20	.23
Lives with parent	16	.15	-1.10	.27	12	.16	-0.73	.47	10	.16	-0.65	.52	11	.18	-0.60	.55	.03	.17	0.18	.86
ID	22	.12	-1.88	.06	.05	.13	0.38	.70	.16	.13	1.19	.24	02	.15	-0.13	.90	.14	.14	1.04	.30
ASD	.01	.12	0.11	.92	04	.13	-0.33	.74	07	.13	-0.51	.61	.05	.15	0.37	.71	.00	.13	-0.01	.99
Physical health	.02	.06	0.28	.78	.15	.06	2.34	.02	.19	.07	2.96	.00	.03	.08	0.81	.42	.10	.07	1.57	.12
Has regular activities	42	.15	-2.87	.01	21	.16	-1.36	.17	52	.16	-3.23	.001	43	.18	-2.33	.02	36	.10	-2.24	.03
SIB-R	.00	.00	0.26	.80	01	.01	-1.32	.19	01	.01	-0.97	.33	.00	.01	-0.73	.46	01	.01	-1.28	.20

Support No	etwork																			
Formal services	11	.05	-2.10	.04	.03	.05	0.50	.61	.01	.06	0.22	.82	.03	.06	0.43	.67	.03	.06	0.43	.67
Parent organizes natural support	04	.15	-0.28	.78	.05	.17	0.32	.75	.19	.17	1.14	.25	.14	.19	0.77	.45	.12	.18	0.70	.49
Parent	.53	.08	6.77	<.001	.52	.08	6.93	<.001	.49	.11	4.09	<.001	.50	.12	4.11	<.001	.54	.11	5.09	<.001
Sibling	.27	.09	3.17	.00	.09	.09	1.02	.31	.22	.08	2.66	.01	.16	.11	1.48	.14	.30	.09	3.24	.001
Other family member	.21	.10	2.16	.03	.49	.10	4.74	<.001	.10	.10	0.93	.36	.43	.12	3.51	<.001	.21	.10	2.17	.03
Family friend	.13	.10	1.33	.19	.10	.10	0.99	.32	.12	.10	1.19	.24	01	.13	-0.04	.97	.14	.10	1.45	.15
Faith community	.29	.10	3.04	.00	.14	.12	1.17	.24	.16	.09	1.70	.09	01	.12	-0.06	.95	.15	.10	1.54	.12
Service provider	02	.08	-0.29	.77	.19	.09	2.05	.04	.13	.10	1.31	.19	.08	.10	0.81	.42	.02	.10	0.23	.82

Supplemental Table 3

Regression Analyses for Extent of Natural Support in Each Life Domain – Multiple Imputations

		Em	ploymen	t		Но	ousing			Rec	reation			Hea	lthcare		C	Commu	nity Acc	ess
Variables	β	SE	t	p	β	SE	t	p	β	SE	t	p	β	SE	t	p	β	SE	t	p
(Intercept)	.58	.40	1.45	.15	.62	.46	1.34	.18	1.15	.45	2.53	.01	.76	.52	1.45	.15	.51	.46	1.11	.27
Parent																				
Black	.75	.17	4.29	<.001	.85	.19	4.56	<.001	.49	.20	2.44	.02	.44	.23	1.90	.06	.40	.21	1.95	.05
AAPI	05	.21	-0.23	.82	.50	.24	2.12	.03	.33	.24	1.27	.17	.40	.27	1.49	.14	11	.25	-0.44	.66
Hispanic	.31	.16	1.94	.05	.03	.18	.17	.86	03	.19	-0.18	.86	.16	.20	0.80	.42	24	.20	-1.19	.23
Income	.02	.02	1.14	.25	.00	.02	.14	.89	.01	.03	0.38	.70	.02	.03	0.86	.39	.00	.03	0.10	.92
Physical health	.12	.06	1.93	.05	.07	.07	1.02	.31	10	.07	-1.48	.14	03	.08	-0.39	.70	03	.07	-0.35	.72
People in family home	.11	.08	1.45	.15	01	.09	-0.07	.94	.19	.09	2.09	.04	.27	.10	2.67	.01	.15	.09	1.69	.09
Familism	.03	.03	0.86	.39	03	.03	-0.96	.34	.01	.03	0.34	.73	.02	.04	0.50	.62	.02	.03	0.54	.59
Adult with	IDD																			
Age	.01	.01	0.99	.32	.00	.01	-0.23	.82	.00	.01	0.03	.98	.01	.01	1.31	.19	.01	.01	1.05	.29
Lives with parent	19	.13	-1.46	.14	17	.15	-1.19	.23	07	.15	-0.47	.64	13	.16	-0.79	.43	.02	.15	0.14	.89
ID	10	.11	-0.97	.34	.05	.12	.42	.67	.12	.12	0.98	.32	05	.13	-0.41	.69	.14	.13	1.14	.25
ASD	.02	.10	0.14	.89	.04	.12	.30	.77	13	.12	-1.06	.29	.17	.13	0.13	.90	.01	.12	0.05	.96
Physical health	01	.05	-0.18	.86	.06	.06	0.96	.34	.14	.06	2.28	.02	02	.07	-0.28	.78	.04	.06	0.65	.52
Has regular activities	32	.13	-2.47	.01	21	.15	-1.46	.14	53	.15	-3.56	<.001	35	.17	-2.09	.04	35	.15	-2.28	.02
SIB-R	.00	.00	0.42	.67	01	.00	-2.23	.03	.00	.00	-0.58	.56	.00	.01	-0.91	.36	01	.00	-1.29	.20

Support Ne	twork																			
Formal services	09	.04	-2.01	.05	.06	.05	1.23	.22	01	.05	-0.22	.83	.05	.05	0.87	.38	.03	.05	0.55	.58
Parent organizes natural support	.07	.14	0.49	.63	.15	.15	0.98	.33	.27	.15	1.74	.08	.28	.17	1.69	.09	.26	.16	1.62	.11
Parent	.52	.07	7.39	<.001	.50	.07	7.03	<.001	.47	.10	4.62	<.001	.53	.11	5.01	<.001	.50	.10	5.09	<.001
Sibling	.28	.08	3.54	<.001	.06	.09	0.71	.48	.19	.08	2.49	.01	.13	.10	1.33	.19	.27	.09	3.11	.00
Other family member	.18	.09	1.96	.05	.41	.10	4.25	<.001	.09	.10	0.96	.34	.41	.11	3.66	<.001	.23	.09	2.50	.01
Family friend	.13	.09	1.43	.15	.10	.10	1.04	.30	.19	.09	2.01	.04	.01	.12	0.09	.93	.13	.09	1.41	.16
Faith community	.32	.09	3.60	<.001	.15	.11	1.30	.19	.11	.09	1.31	.19	.03	.11	0.25	.80	.17	.09	1.83	.07
Service provider	.07	.07	1.01	.32	.27	.09	3.11	.00	04	.08	-0.48	.63	.03	.09	0.31	.75	.04	.09	0.43	.67