



FINDS

Family & Individual Needs
for Disability Supports

Community Report 2023

rtc on community living

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The Arc

*For people with intellectual
and developmental disabilities*

2023 Family and Individual Needs for Disability Supports

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About FINDS

The Family and Individual Needs for Disability Supports (FINDS) survey provides insights and understanding of the experiences of families supporting a family member with intellectual and developmental disabilities (IDD). It is critical research to inform better policy development.

An estimated 7.3 million people with IDD live in the United States (Larson et al., 2018). About 1.6 million individuals receive formal supports through their state's developmental disability agency (Larson et al., 2022). Formal supports may include Medicaid Home and Community Based Services (also known as "waivers") that provide in-home, residential, employment, or other supports that enable persons to live in the community. More than half (62%) of people with IDD receiving a Medicaid-funded service live with their families (Larson et al., 2022). This means families are essential in providing care to their family members with IDD. Supports

provided vary widely and include behavior, health, and medical supports (such as therapies); as well as transportation, assistive technologies, and assistance with daily living activities such as preparing meals, personal care, shopping, and so on.

The Family and Individual Needs for Disability Supports (FINDS) survey was initially conducted by The Arc of the United States in 2010. It was updated in 2017 and in 2023 through a collaboration between the Research and Training Center on Community Living (RTC/CL) at the University of Minnesota and The Arc. The purpose of FINDS is to understand the experiences of families who provide supports to a family member with IDD. An estimated 53 million people support a family member who is aging or has a disability (AARP and National Alliance for Caregiving, 2020). Important questions exist about families who provide such supports:

1. What are the challenges families face in meeting the support needs of their family members?
2. What are the economic implications of caregiving?
3. How does caregiving affect caregivers, and what supports do they need?

A better understanding of the experiences and needs of caregivers can help policymakers and others support caregivers in this critical role.

A note about language

We recognize that some people prefer identity-first language (such as autistic adults). In contrast, others prefer person-first language (such as someone with an intellectual disability). After consultation with our Self-Advocate Advisory Committee, we used person-first language in this report.

How We Conducted the Survey

The FINDS survey was made available online in January and February of 2023. In order to improve the diversity of respondents, the survey was in English, Spanish, or French. In addition, recruitment efforts included working with partners to distribute the survey. Participants responded to the survey in English and Spanish. Caregivers who were family members or friends of someone with IDD and provided supports took part in the survey. Direct support professionals or other caregivers whose primary relationship with individuals with IDD was as a paid supports person were not part of the sample. More than 3,000 people (3,118) took part in the survey. Individuals from every state, the District of Columbia, Puerto Rico, and Guam participated.

About the Family Member Providing Supports

Participants were primarily female (86%), between the ages of 45 and 64 (52%),

I would like there to be 24/7 support for my son in the family home. He would get this support in any other residential setting, but since he lives with me, it's expected that I will do everything over 40 hours a week for free. It's just too much to expect of any person. It's no wonder that family caregivers go into crisis. Can't live on four hours of sleep indefinitely.

self-identified as White (82%), and were married (66%). Most had been born in the United States (93%) and lived in a suburban community (60%). Two-thirds reported graduating from college. About 1/3 (36%) reported annual household incomes of less than \$60,000. The remaining 64% of the participants reported yearly household incomes of \$60,000 or more. Most of the participants reported being parents of the person receiving supports (75%), followed by being a child (7%) or sibling (6%).

Reflecting the Diversity of the United States

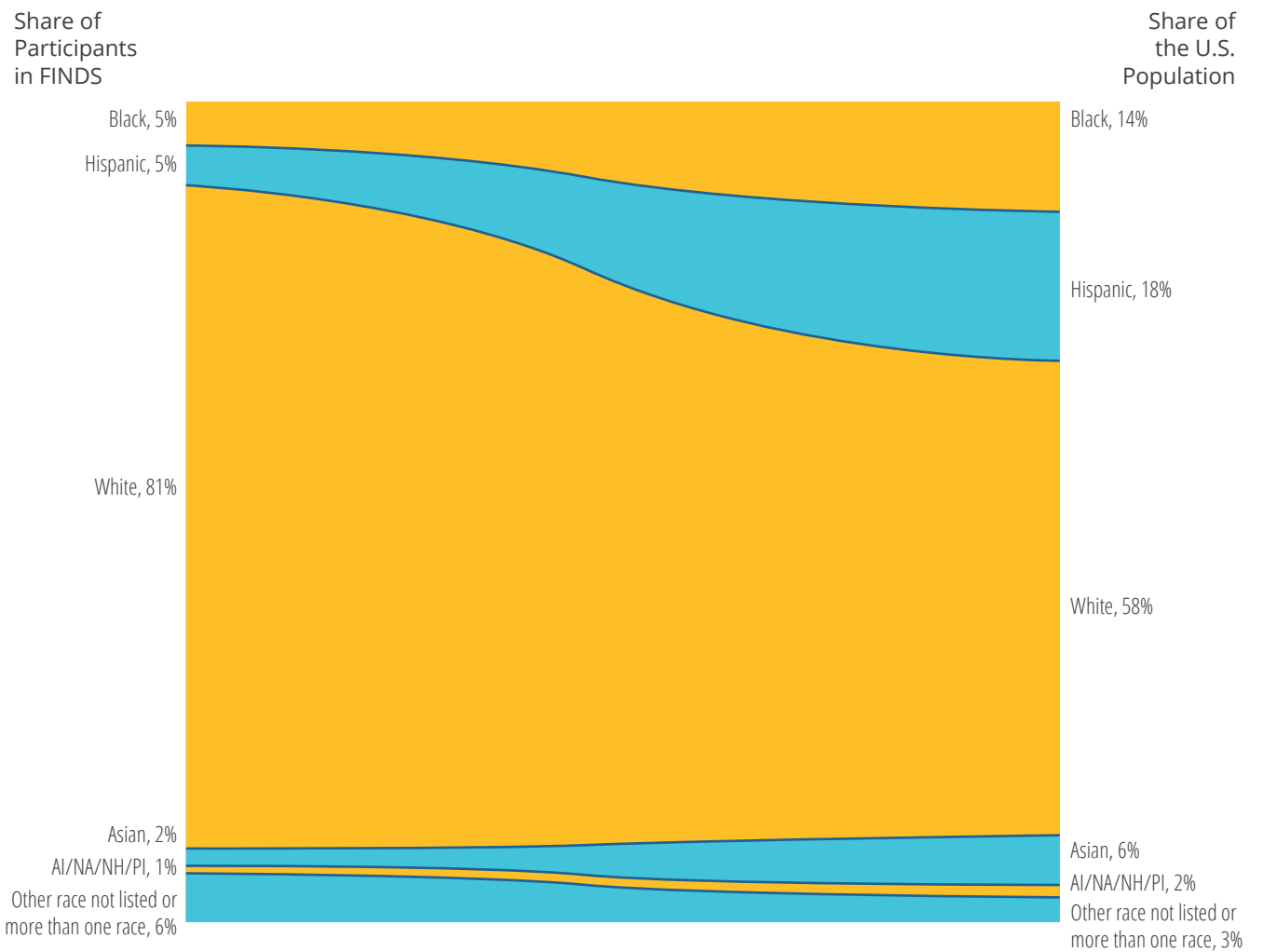
Due to the limited number of individuals in some groups (fewer than 5 people), some groups were combined. Individuals from the American Indian, Alaska Native, Native Hawaiian, and Pacific Islander groups (AI/AN/NH/PI) were combined for these analyses. Individuals who self-identified as having more than one race or ethnicity were included in more than one group.

While the demographic backgrounds of the participants are not a true reflection of the population of the United States, it is more diverse than previous FINDS surveys. The lack of diversity and small group sizes should be considered when reading the findings in this report.

Differences across income were examined by comparing individuals who reported being above or below a household income of \$60,000. When caregiver responses differed between income or race groups, the

differences are noted in each section. In many areas, caregivers of different backgrounds reported similar experiences, so differences by income group or race are not discussed in those sections. The demographics of the FINDS participants should be considered when reviewing the findings. In particular, the sample had a higher household income and education level than the U.S. population. The participants were also mainly female and White.

Figure 1: Participants in the FINDS Survey Do Not Adequately Reflect the Diversity of the U.S. Population



Who Participated?

Table 1: Characteristics of Family Members Who Provide Supports in the FINDS

Gender (N=3,024)	
Female/transfemale	86%
Male/transmale	14%
Non-binary/third gender	<1%
Age (N=3,111)	
18 to 24	<1.0%
25 to 34	7%
35 to 44	15%
45 to 54	22%
55 to 64	30%
65 to 74	21%
75 or older	5%
Race (N=3,035)	
American Indian/Alaskan Native	<1%
Asian	2%
Black/African American	5%
Hispanic/Latino	5%
Native Hawaiian/Pacific Islander	<1%
White	82%
Other race not listed	1%
More than one race	5%
Born in the US (N=3,114)	
Yes	93%
No	7%
Education Level N=3,108)	
Kindergarten – 12th grade, no diploma	<1.0%
High school diploma or GED	8%
Some college	25%
Bachelor's degree	33%
Post-graduate education	34%
Community Type (N=3,104)	
Urban	18%
Suburban	60%
Rural	22%
Relationship Status (N=3,107)	
Married	66%
Living with a partner	4%

Widowed	6%
Separated	3%
Divorced	14%
Single, never married	7%
Household income (N=2,640)	
No income	2%
Less than \$14,999	4%
Between \$15,000 and \$21,999	5%
Between \$22,000 and \$39,999	11%
Between \$40,000 and \$59,999	14%
Between \$60,000 and \$99,999	27%
Between \$100,000 and \$200,000	28%
Above \$200,000	9%
Relationship to the Person You Support (N=3,034)	
Parent/step-parent	75%
Foster parent	2%
Grandparent	2%
Sibling	6%
Other family member (such as aunt, uncle, cousin)	2%
Spouse/partner	2%
Child	7%
Friend or neighbor	2%
Some other relationship	2%

What We Learned

Key Findings

When the FINDS was conducted in 2017, caregivers reported many challenges that led to high stress and fatigue levels. The scope, intensity, and duration of caregiving responsibilities for FINDS caregivers were greater in 2017 than reported by other caregivers such as in the Caregiving in the U.S. survey. This survey was conducted by the National Alliance on Caregiving and AARP and has eldercare as its primary focus. FINDS participants also reported economic strain stemming from negative impacts on work from their responsibilities related to providing supports to their family members.

In the years since 2017, the COVID-19 pandemic led to efforts to reduce the transmission of the disease to vulnerable people, leading to an even greater reduction in services and supports as children were sent home from school and day supports and employment programs closed. During this time, the direct support workforce experienced a loss of significant numbers of workers, exacerbating an already difficult situation (McCall et al., 2021). Participants in the 2023 FINDS noted that services continue to be affected by the workforce crisis.

The effects of the direct support workforce shortage on participants and their family members with IDD are apparent and are likely

causing strain as families' lives are disrupted. The lack of reliable supports means that participants in this survey were more likely to report that they gave up work entirely to provide support and were experiencing more stress than in 2017. Participants also reported providing more supports than they used to due to the difficulty in finding direct supports professionals. Their family members with IDD are also negatively affected. They are receiving fewer supports, and are having fewer opportunities to make choices, are more socially isolated, and are less able to fully participate in their communities. Finding supports for families, such as respite, continues to be a challenge.



Some of the outcomes reported by caregivers, such as health status and stress levels, differed across race and ethnicity and by household income. There were also significant differences in the extent to which caregivers from different backgrounds reported that their family members used particular supports. We cannot determine if these differences are related to access issues or the acceptability of the available supports, however.

Family caregivers report that supports and services decreased during the COVID-19 pandemic. The situation has been ongoing due to the direct support workforce shortage.

- 68% of family caregivers reported that the direct support workforce crisis had negatively affected the supports that their family members received.
- 81% of family caregivers provided more supports due to decreased available supports and services.
- 35% reported that their family member is on a waiting list for government-funded supports and services.
- 73% paid more out-of-pocket, and 37% report difficulty paying for supports and services.
- Participants reported that their family members are experiencing various negative effects from the decreased availability of supports, including access to therapies, having work hours cut, losing their job, or having schools/daycares cut hours or close.
- Family caregivers reported that the negative effects related to their caregiving duties have increased since the 2017 FINDS Survey.

- The number of caregivers who reported feeling very or extremely stressed has increased from 48% in 2017 to 54% in 2023.
- Nine in ten caregivers reported some impact on their employment related to their caregiving responsibilities.
- 41% reported leaving employment to provide supports to their family member.
- Half of all participants (50%) agreed or strongly agreed that they were under financial strain due to providing supports.

Family caregivers also reported on supports that would be helpful. These included:

- Respite
- Being paid for providing supports
- Having paid leave
- Having an employee assistance program
- System navigation assistance

What this Means for Families

The reported challenges of the direct support workforce have significant policy implications. As services and supports have become increasingly individualized, and as the population ages, there is an urgent need for more workers trained to provide community supports to people with various needs. The high number of individuals waiting for services while living in the family home is an additional concern as the caregiving population ages. The economic burden of caregiving has implications as aging caregivers reach retirement and have increased care needs of their own.

Since 2017, the Administration on Community Living has taken steps to address the workforce

The biggest additional support for me would be affirming mental health care. I have completely neglected my need for therapy because we just don't have money for it.

Earlier in my journey, I needed help navigating the different programs that were available. I felt like it was some kind of secret code and no one would offer me help unless I knew the password or something.

crisis and the need to better support family caregivers. In 2022, ACL launched the National Technical Assistance and Resource Center, which will provide technical assistance to states and service providers to improve direct support workers' recruitment, retention, training, and professional development. Change will take some time, however. There needs to be attention to other policies across states and Medicaid programs that will aid families and ensure that people receive the supports they need. These range from increasing pay rates to attract direct support workers to the field, to expanding access to waivers and family support services. In addition, the flexibility allowed by the waivers to allow for paid family caregivers in certain circumstances should remain.

The ACL also released a national strategy to support caregivers in 2022. This strategy includes five goals aimed at improving outcomes for family caregivers:

- Improved awareness of and outreach to family caregivers
- Inclusion of family caregivers in the care team
- Services and supports for family caregivers
- Financial and employment protections
- Data, research, and best practices

While some of these goals may require additional legislation and sources of funding, some actions can be taken within the context of current programs to improve outcomes for family caregivers.

One issue that must be addressed is the inequities and disparities in access to services and supports experienced by families from

under-resourced communities, including rural areas, lower-income households, and culturally, linguistically, and racially diverse families.

Other systemic issues need to be addressed, including the lack of affordable housing and limited transportation options, which make it more difficult for individuals with disabilities to live in their communities, access community resources, and obtain and maintain employment. Ultimately, the lack of housing opportunities and accessible, reliable transportation falls onto families to provide those supports.

The participants in this survey identified key areas that would make their roles easier. These include ensuring that respite is available, that direct support workers are trained and well-paid, that family caregivers can be paid for their supports, and that systems are made simpler and easier to access. Having improved access to systems navigation and supports coordination, including those using self-directed supports, is needed for family members providing support to a person with IDD and to the person themselves. Systems are overly complex and difficult to navigate, adding to families' challenges in accessing and using services.

Participants' Experiences

How Much Support do Family Caregivers Provide?

Most of the caregivers (70%) live with their family members, but there were some differences across race. Caregivers who identified as White or Black/African American were less likely to report living with their family members (66%

for both). More than 70% of the other groups reported living with their family member. People who identified as Asian or Latine were the most likely to live with their family members (89% and 86%). Among the sample, 40% reported caring for a child under 18, with 11% caring for two or more children with a disability; 20% provided 41–80 hours of supports, and another 41% provided more than 80 hours per week.

Caregivers were more likely to provide supports to adults (60%), with 15% supporting two or more adults. People who supported adults were less likely to report high numbers of hours providing supports. Among them, 17% provided supports between 41 and 80 hours per week, and 33% provided more than 80 hours.

Caregiver Well-being

Health Status. Overall, participants reported that their health was good (38%), very good (27%), or excellent (8%; See Figure 1). Fewer reported poor (8%) or fair (22%) health. There was little change

in self-reported health compared to the FINDS 2017 survey. Self-reports of health and the extent to which providing supports affected the participants' stress differed across race. Black or African-American (73%) and White caregivers (74%) reported their health as better (good, very good, or excellent) than did the other groups, followed by people who reported more than one race (68%), Asian (66%), Latine (60%) and AI/AN/NH/PI (53%). More than half of family caregivers (58%) other than Black or African-American caregivers (43%) reported that providing supports harmed their health.

Caregivers with lower incomes (below \$60,000) were less likely to report better health (61%) than caregivers with incomes of \$60,000 and over (78%). Nearly 6 in 10 caregivers in both groups, however, reported that providing supports made their health worse (57% and 59%). Of all caregivers, 73% reported that they were under physical strain.

Figure 2: FINDS Participants Self-reported Health Status is Similar in 2017 and 2023

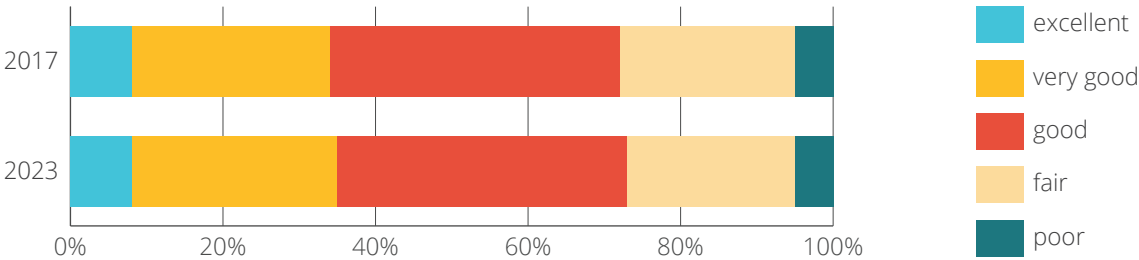
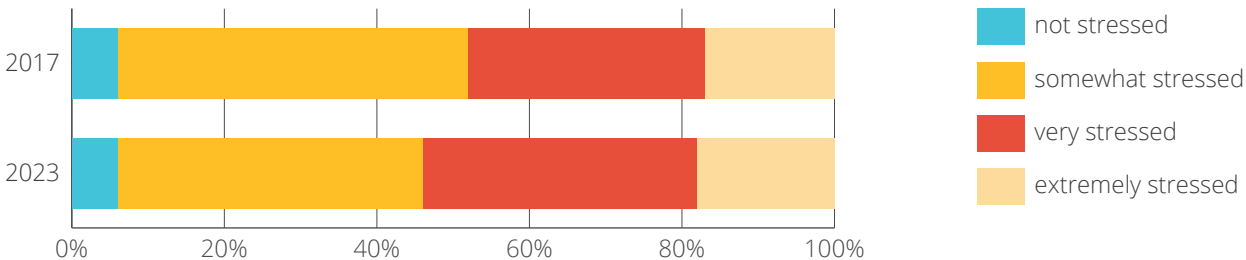


Figure 3: More 2023 FINDS Participants Report Being Very Stressed than in 2017



Stress Levels. Nearly all caregivers report some level of stress (94%; [See Figure 2](#)). The extent to which caregivers reported being very or extremely stressed, however, differs across race. More than half of all caregivers, except for Black or African-American caregivers (40%), reported being very or extremely stressed. Stress levels have increased for family caregivers since the FINDS 2017 survey. Caregivers reporting no stress or being somewhat stressed decreased from 53% of respondents in 2017 to 46% in 2023. Those reporting being very or extremely stressed have increased from 48% to 54%.

Economic Outcomes Related to Providing Supports

Nine of ten caregivers reported at least one employment-related effect related to supporting their family members ([See Figure 3](#)). The most common was coming to work late or leaving early (77%). This is somewhat higher for people with higher incomes (79%) than those with lower incomes (74%). People with lower incomes were more likely to report negative impacts on employment than those with higher household incomes. There are no significant differences across race related to employment outcomes. Caregivers with household incomes below \$60,000 were more likely to report taking a leave of absence (47% vs. 38%), cutting back their work hours (56% vs.

Figure 4: More 2023 FINDS Participants Report Retiring Early or Giving Up Work to Support Their Family Member than in 2017

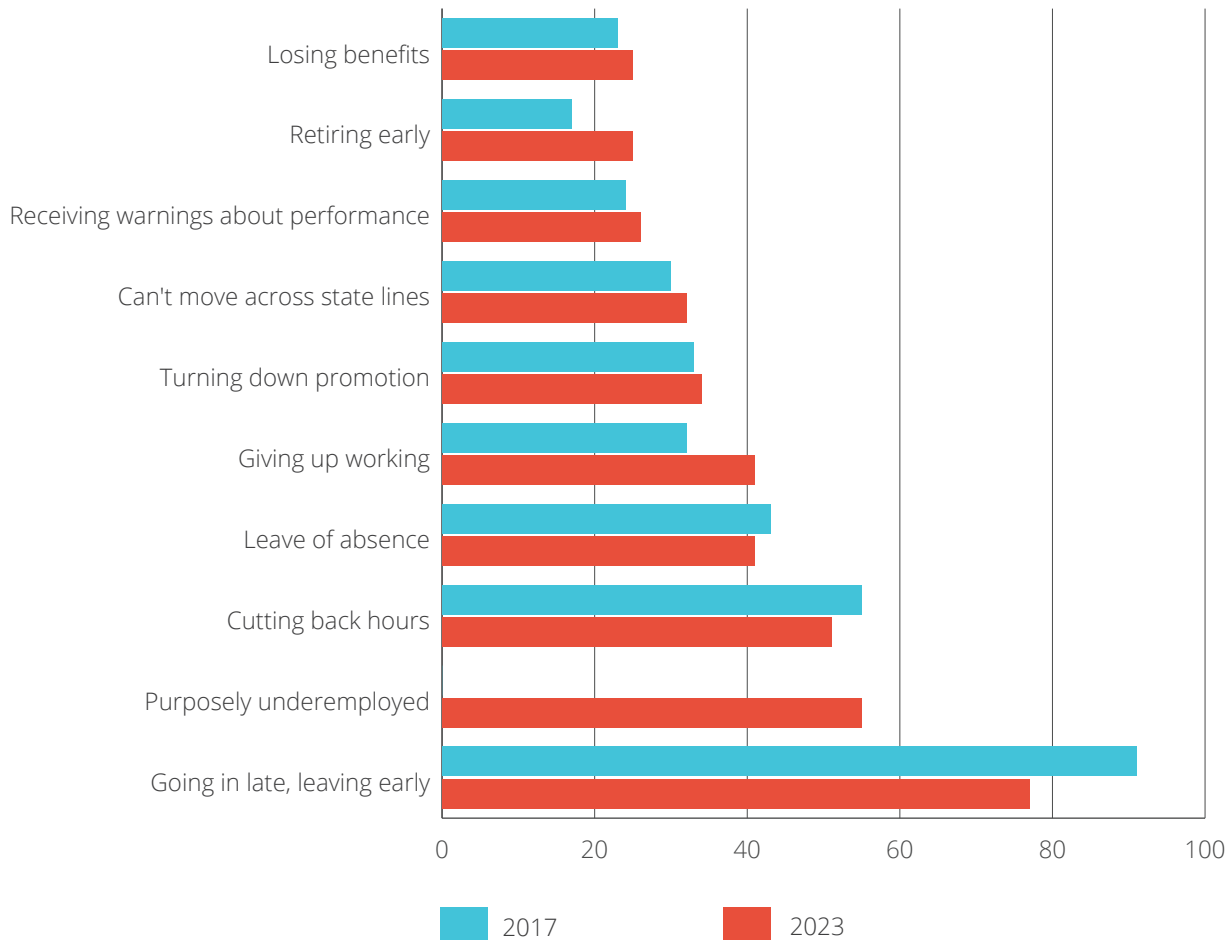
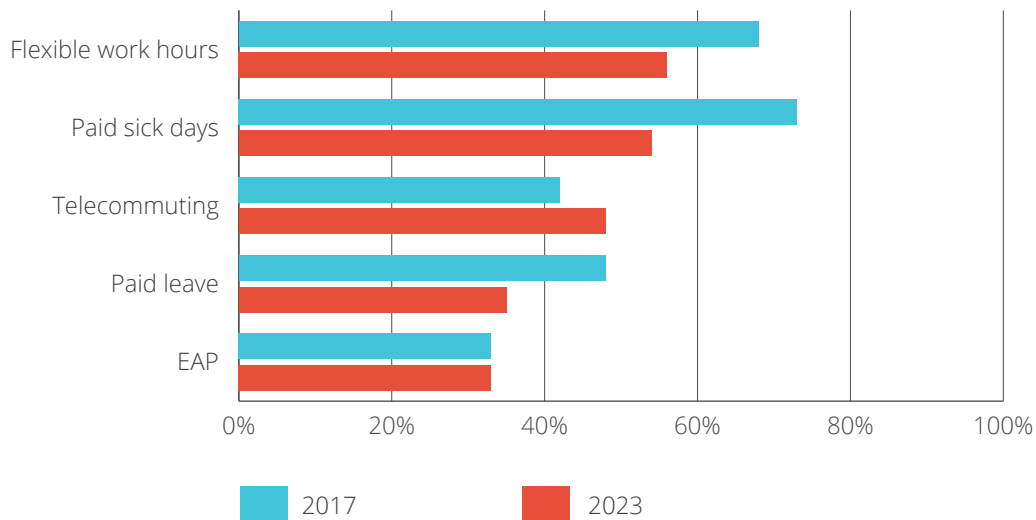


Figure 5: Fewer 2023 FINDS Participants Report Having Employer Benefits that Support Their Caregiving Role than in 2017



48%), being purposely underemployed (59% vs. 53%), losing benefits (34% vs. 23%), giving up work altogether (48% vs. 37%), and receiving warnings about attendance (36% vs. 22%) than caregivers with household incomes higher than \$60,000. Finding care so they could go to work was cited as a major problem by 38% of participants and 29% identified adjusting their work schedule and meeting their work responsibilities as a major problem. The number of participants who reported work impacts was 95% in the 2017 FINDS survey. Participants in the 2023 survey were more likely than those in 2017 to report leaving employment altogether (41% vs. 32%) or retiring early (25% vs. 17%) due to their caregiving responsibilities. The question about being purposely unemployed was not asked in 2017.

Supportive Employer Benefits

Caregivers were asked to report if their employer provided any benefits supporting their caregiver role (See Figure 4). These also differed by household income level. Caregivers with higher reported household incomes were likelier to report helpful employer benefits than caregivers with lower household incomes. These benefits included flexible work hours (60% vs. 51%), the ability to work from home (55% vs. 36%), Employee Assistance Programs (37% vs. 29%), paid time off to provide supports (41% vs. 27%) and paid sick time (63% vs. 40%). More caregivers with higher incomes (69%) also reported understanding supervisors and coworkers than those with lower incomes (54%).

Overall, participants reported that their employer benefits decreased since 2017. Decreases included those reporting paid sick time from 73%

One general clearinghouse for access to information and services. Currently, you have to sift through various agencies and government programs to find, hopefully, the information or services you are trying to find.

Just something that is easily digestible, with easy action item steps. The DD system is so complex, and as busy caregivers we hardly have time to attend trainings, so when we do, it is most helpful if they are short, concise, and to the point.

in 2017 to 54% in 2023, flexible work schedules (68% to 56%), and paid leave (48% to 35%). The only area that improved since 2017 was the ability to telecommute or work from home (42% in 2017 to 48% in 2023).

Policy Recommendations to Help Caregivers Financially

The FINDS asked caregivers to indicate which policy recommendations would benefit them financially (See Figure 5). These included both government programs and policy changes, as well as employer-provided benefits. Financial support, such as paying family members to provide supports (94%) and income tax credits for caregivers (85%), was cited most frequently as helpful or very helpful, followed by paid leaves

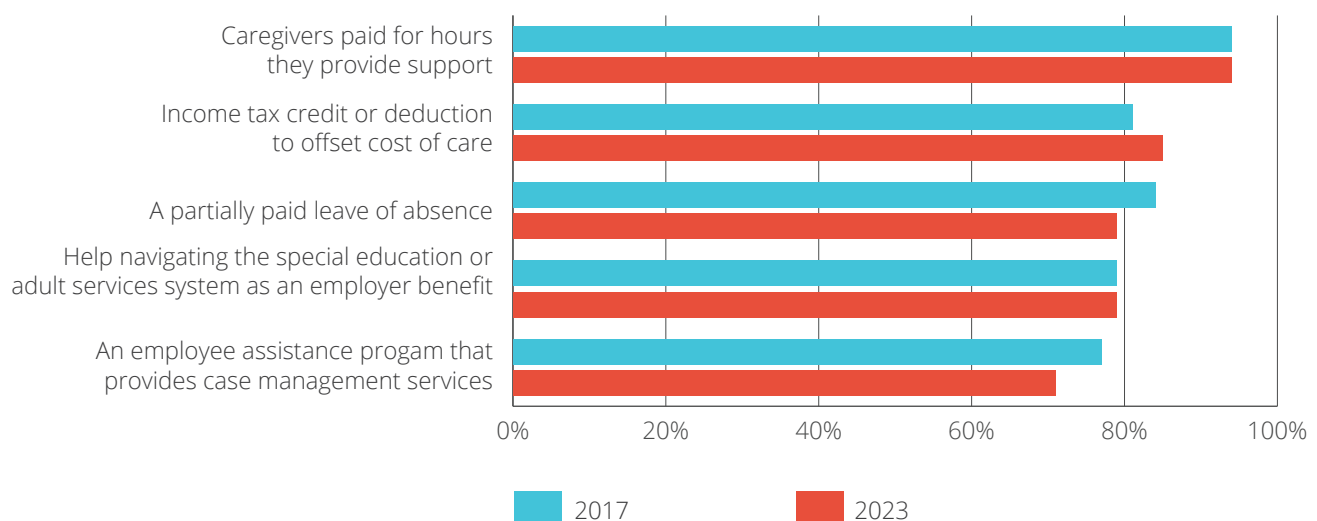
of absence (79%), system navigation assistance (70%) and an employee assistance program that includes case management (71%). In 2017, participants also highly endorsed paying caregivers (94%). Their endorsement for income tax credits or deductions (81%) was lower, while paid leaves of absence (84%) and employee assistance programs (77%) were higher.

About the Family Member Receiving Support

Demographics

Family members with disabilities receiving supports were more likely to be male (60%). While most reported being White (75%), the reported

Figure 6: FINDS Participants in 2023 and 2017 Overwhelmingly Endorse Paying Caregivers for the Hours They Provide Support as Helpful or Very Helpful





race for people receiving supports was more diverse than for the caregivers. Most people receiving supports were between the ages of 22 and 64 (59%), 39% were aged 21 and under, and 2% were 65 and older. Six in ten (59%) were reported to have an intellectual disability, 50% were reported to have autism spectrum disorder (ASD), 40% had a communication delay or speech disorder, 36% had any developmental delay, and 36% had a mental or behavioral health diagnosis. Fewer than a third were reported to have a variety of developmental disabilities (See Table 2).

Table 2: Characteristics of Family Members with Disabilities

Gender (N=3,024)	
Female/transfemale	38%
Male/transmale	60%
Non-binary/third gender	2%
Age (N=3,032)	
0 to 5	3%
6 to 13	12%
14 to 21	24%
22 to 34	38%
35 to 44	13%
45 to 54	5%
55 to 64	3%
65 to 74	1%
75 and older	1%
Race (N=2,952)	
White	75%
More than one race	8%

Black/African American	7%
Hispanic/Latino	5%
Asian	3%
American Indian/Alaskan Native	1%
Other race not listed	1%
Native Hawaiian/Pacific Islander	<1.0%
Disability Type (N=3,030)*	
Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD)	29%
Autism Spectrum Disorder (ASD)	50%
Any developmental delay	36%
Intellectual disability	59%
Cerebral Palsy	16%
Chronic health conditions	26%
Communication or speech delay/disorder	40%
Alzheimer's/Other forms of dementia	3%
Deaf/Hard of hearing	8%
Down Syndrome	15%
Fetal Alcohol Spectrum Disorder (FASD)	3%
Blind/Limited vision	9%
Epilepsy/seizure disorder	23%
Mental/behavioral/psychiatric diagnosis (such as anxiety, depression, mood disorder, bipolar, schizophrenia)	36%
Physical disability or limited mobility	25%
Traumatic brain injury	6%
Some other disability	13%

* Participants were allowed to check more than one

Connecting with other parents who envision a life of self-determination for their son or daughter. Many parents in my area are planning to put/have put their loved one in institutional housing, group home, and sheltered employment. My daughter wants to go to college, work in the community, and live with someone that she chooses. She prefers community activities versus activities solely for people with disabilities. I would like to find other parents to connect with that have been able to support their loved one to attain some of the same goals.

Support Needs

Caregivers reported providing a wide range of supports to their family members. In general, caregivers were more likely to provide supports for Instrumental Activities of Daily Living (IADL) than other types of supports. These include managing money, making calls, transportation, and household management.

ADLs. These include personal hygiene, getting dressed, eating, or toileting (See Figure 6a). The types and average number of supports family caregivers provided have not changed since the 2017 FINDS survey. Supports for dressing and grooming were the most common (68%), followed by bathing or showering (62%). Caregivers also provided supports for eating (52%), using the restroom or managing incontinence

(46%), mobility (29%), and getting out of bed or chairs (21%). Caregivers reported providing an average of 3 ADL supports. More than half (56%) found this somewhat challenging, and 23% found it very challenging. More than half (56%) also reported that their family member needs more supports for ADLs.

IADLs. Caregivers reported providing an average of 9 IADL supports for their family members (See Figure 6b). More than 80% provided supports with household chores (85%), transportation assistance (84%), money management (84%), assistance with paperwork (84%), social arrangements (82%), and arranging for or monitoring services or direct support professionals (81%). Other supports included providing direct financial supports (79%), supporting

Women/moms lead the charge in these matters. I have tried to connect with other fathers in this situation but that has proven difficult. I don't know what supports I would like exactly, but I can see the hole in my life from not having more friends who understand this stuff.

We have been waiting on a waiver for years, so I work overnight 10–12 hour shifts, come home, sleep for 45 minutes, drive him to work. Come back home and sleep for an hour or two before going back to pick him up. Then I come back home, get him lunch and showered. Off to go do an activity in the community, grocery shopping, or doctors appointment. Back home to make dinner, shower and off to work I go.

recreational activities (77%), home maintenance (77%), coordinating community services, using the phone (62%), and assisting with communication (39%). More than half of those providing supports (53%) found this somewhat challenging, and 40% found it very challenging. Nearly 8 in 10 (77%) reported that their family member needed more supports.

Health-related supports. The most common health-related supports provided was coordinating their family member's health care (91%), followed by managing medications (84%), performing therapies (55%), and performing medical procedures (such as tube feeding; 33%) (See Figure 6c). Caregivers reported supporting an average of 3 health-related needs. More than half (55%) found this somewhat challenging, and 27% found it very challenging. More than 6 in 10 (62%) reported that their family member needed more supports in this area.

Social and Emotional Supports. Nearly all participants (99%) reported providing social and emotional support (See Figure 6d). These include supporting their family member to explore their interests and learn new things (85%), providing emotional and affirmational supports (84%), supporting the person to

spend time with the people who were important to them (84%), supporting the person to express their wants and needs (78%), and supporting the person to be a valued member of their community (78%). FINDS participants provided an average of four of these supports. More than half (53%) found it somewhat challenging, and 38% found it very challenging. Nearly 8 in 10 (78%) reported that their family members needed more social and emotional supports.

Caregiver and Family Member Outcomes

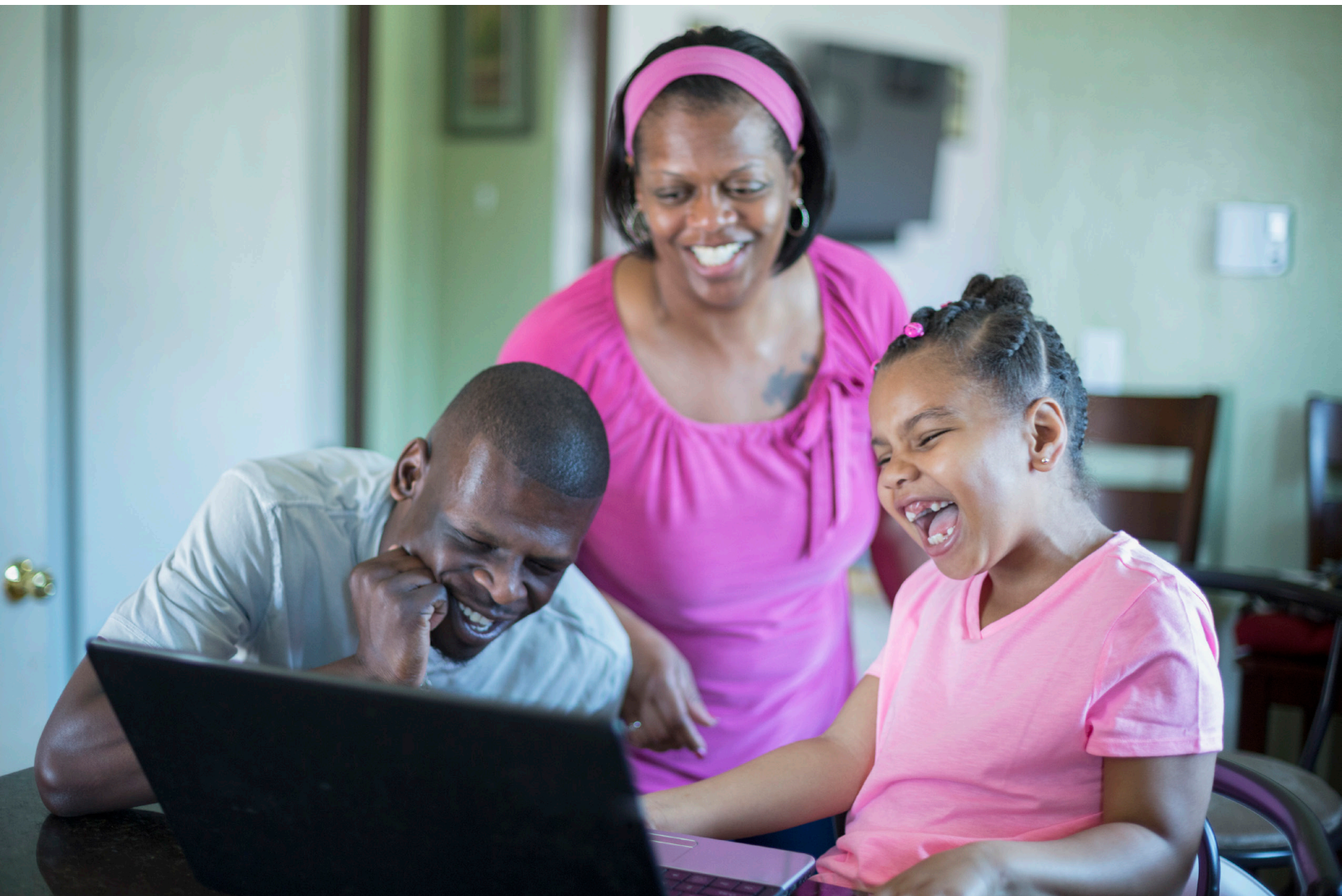
The remainder of the report provides a summary of the supports and services an individual or family may receive and to what extent these supports are meeting the needs of the individual or the FINDS participant. These may include outcomes related to employment support for the individual with IDD or outcomes related to the well-being of the family member who provides support. We are using the Charting the LifeCourse framework to talk about these findings.

Charting the LifeCourse

The Charting the LifeCourse (CtLC) framework is based on the idea that all individuals and families go through different life stages and each of these stages has different roles and expectations for each family member. In addition, experiences in one life stage prepare us for future life stages. CtLC calls this the trajectory. When planning supports, thinking about what a good life is like for individuals and their families can be useful. Supports can be divided into three categories or buckets: Discovery and Navigation, Connecting and Networking, and Goods and Services. People have roles and tasks and need supports in different areas of life, called the

Life Domains. These domains are Daily Life and Employment, Community Living, Healthy Living, Safety and Security, Social and Spirituality, and Advocacy and Engagement (Reynolds et al., 2018; <https://www.lifecoursetools.com/>).

The CtLC framework has been adopted by 22 states as part of a community of practice (<https://supportstofamilies.org/>). These states incorporate CtLC principles and tools into their policy and practice, supporting individuals with IDD and their families. The remainder of this report describes outcomes for the family members who provide supports and the person being supported in the context of the CtLC framework.



We need help! As aging caregivers, we are basically on our own unless a crisis occurs. There is NO way to plan for the future of our family member with disabilities. The stress is awful and just keeps on and on. The waiting lists continue to grow and grow and nothing positive happens. So discouraging!!!

Discovery and Navigation

Discovery and Navigation is the first bucket of support and includes the information individuals and families need to understand or decide. It also includes helping individuals and families find information or navigate systems.

Help with Navigating and Planning Services

More than half of all family caregivers (59%) reported needing navigating and planning services, a slight increase from 2017, when 57% reported needing such assistance. This group includes families who were receiving this support but needed more assistance and those who did not receive any support but reported that it was needed. More than a quarter (26%) reported that they had this assistance, and 19% reported that their family did not use this service. There were differences across race and ethnicity in the need for additional support. Caregivers who identified as AI/AN/NH/PI were the most likely to report that they needed more assistance with system navigation (74%), followed by caregivers who identified with more than one race/

ethnicity (61%), White (57%), Black or African American (56%), and Asian (49%). The differences across income levels were not significant.

Entitlements, IDD Services, Technology, Laws and Policies, and Advocacy and Engagement

Nearly two-thirds (60%) of caregivers reported needing more information about entitlements, services, and policies. This could be because they did not receive this information or needed more information than they were getting. Almost one in five (19%) reported that they received this support, while 21% reported they did not.

Caregiver Training

Caregivers were asked how helpful they thought online training would be. Most caregivers (85%) thought it would be helpful or very helpful. Somewhat more thought that in-person training was helpful or very helpful (90%). Participants were asked what training topics would be most beneficial. The most-commonly mentioned topics included behavior supports for challenging

There is a tremendous lack of housing for people with disabilities, that is my greatest fear. I'm fearful that when I am incapacitated that she will fall through the cracks and her safety will be compromised. I am also concerned that there will be too little oversight and her life will be less productive.



behavior, training about the service system and how it works (ranging from Medicaid and waivers to SSI), how to manage self-directed services and providers, and training and supports related to future planning for their family member.

Connecting and Networking

The second bucket of support is Connecting and Networking, which includes connecting with others who have similar experiences.

Provide Online and In-Person Opportunities to Connect

Participants were asked how helpful connecting with other caregivers in person or online would be for them. Most participants (80%) thought having available supports would be helpful or very helpful. Participants who identified as Latine were more likely to prefer in-person training (89%) over online training (81%).

Receives Family-to-Family Connecting Activities

Although most participants agreed that connecting with other families would help them, few reported receiving this type of support. One in four participants (25%) reported receiving family-to-family connecting supports. Another 23% reported that while they did receive some family-to-family connecting activities, they could still use more. About half (52%) reported not having these supports, and half of those participants said they needed them.

Goods and Services

The third bucket is Goods and Services. These are the things people buy or use in their daily lives. They may or may not be disability-specific items or services. They can be from public or private organizations or businesses. This report is going to focus on disability-related goods and services.

Has a Support Plan

A support plan is used to identify what kinds of goods and services are needed to support someone. For example, plans may include needed medical equipment or details about what kinds of support an individual needs and who will provide that support. Most participants (64%) reported that their family member had an individualized service plan (ISP). This is somewhat lower than in 2017, when 68% of participants reported that their family member had a support plan. In 2023, only 52% of Black or African-American participants said the person they supported had an ISP. Participants in lower-income households (58%) were also less likely to report having an ISP than those with higher incomes (66%). For those who had support plans, eight in 10 participants (84%) reported that they and the person they supported helped develop the ISP. More than half (55%) of participants reported that the plan met their family member's needs. (Note: Generally, if a person has paid supports, they have a support plan. However, individuals and families may not be aware of it.)

Funding Sources

Participants were asked what funding sources were used to pay for the supports the person they supported received (See Figure 7). The most common sources were family income (80%), family savings (70%), and Social Security income (63%). Six of ten participants (62%) reported that the person also received unpaid supports. About half of the participants reported that a Medicaid Home- and Community-Based waiver paid for the person's supports (49%). About a third (35%) reported receiving some other Medicaid support.

There were some differences in funding sources used across race and income groups. People who identified as White (52%) were much more likely to report using a waiver to pay for supports than other groups. In comparison, people who identified as Asian (90%) were much more

Figure 7a: Number and Average of Activity of Daily Living Supports Provided

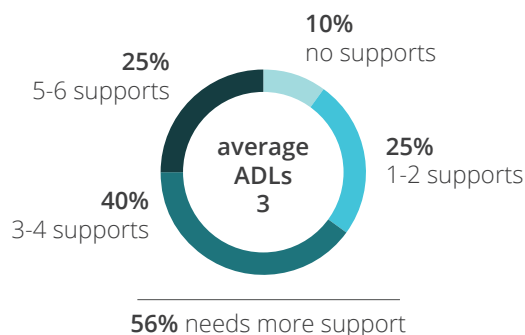


Figure 7b: Number and Average of Instrumental Activity of Daily Living Supports Provided

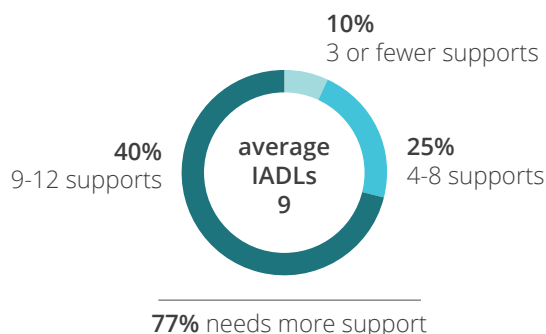


Figure 7c: Number and Average of Health Supports Provided

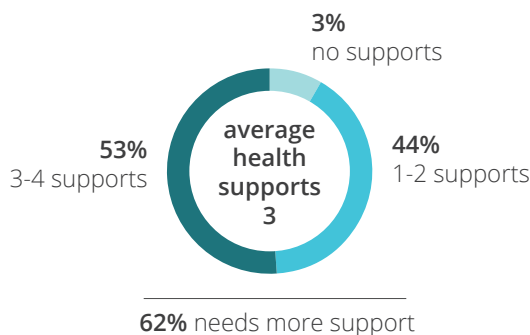
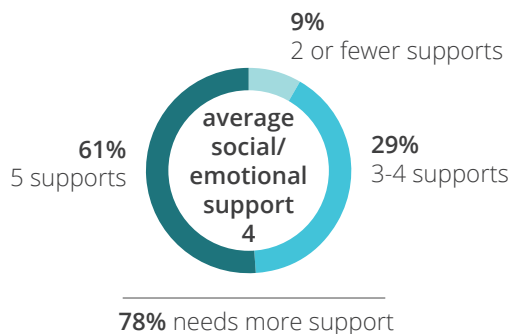


Figure 7d: Number and Average of Social and Emotional Supports Provided



How can you find affordable, supported housing that will work out long term? Seems like the not-for-profits connected to HCBS aren't involved in federal low-income housing programs and it looks like there are closed waiting lists for them anyway. So how can I find affordable housing for my person, in my community, close to her job?

likely to report using family income to pay for supports. AI/AN/NH/PI participants were likelier to report unpaid supports (83%). Participants from lower-income households were more likely to report using some type of Social Security income (such as Supplemental Security Income) to pay for supports (67%).

In comparison, higher-income households were more likely to report using family income (82%). The use of Medicaid waivers also differed across household income groups. Households earning over \$60,000 per year were more likely to report using a waiver (52%) than those with lower incomes (45%).

How services and supports are paid for have changed somewhat since 2017. More participants reported having a Medicaid waiver in 2017 (54%) than in 2023 (49%). And more people reported paying for support from family savings in 2023 than in 2017 (70% vs. 63%).

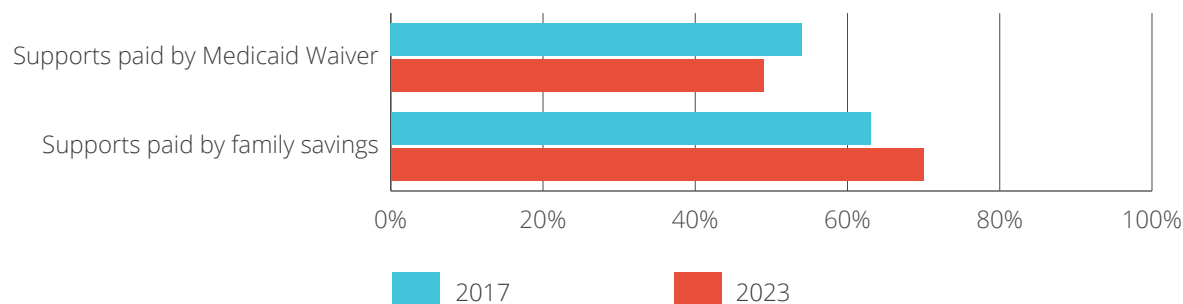
Paying for Supports

More than a third of all participants (37%) said that paying for supports was a major problem. This is higher than in 2017 (33%). There were differences across income, race, and ethnicity. Participants with less than \$60,000 (47%) reported difficulties paying for supports much more frequently than those in higher-income households (30%). A third (33%) of White participants reported that paying for supports was a major problem, as did 56% of AI/AN/NH/PI, 44% of Asian, 49% of Black or African American, 52% of Latine, and 50% of participants identifying more than one race. Half of all participants (50%) agreed or strongly agreed that they were under financial strain due to providing supports. This is lower than the 59% who reported this in 2017.

Waiting for Services

About a third (35%) of participants reported that the person they supported was on a waiting list

Figure 8: More people used family savings to pay for supports in 2023 than in 2017. More people used Medicaid Waivers in 2017 than in 2023.



The staffing shortage is a HUGE problem that affects virtually every aspect of my son's life, which then affects my life. I care for him on weekends more because his house is short-staffed and/or poorly-staffed on weekends.

for government-funded services or supports. Most reported waiting for a Medicaid Home and Community-Based Services waiver (42%), followed by residential supports outside of the family home (21%), some other supports (15%), behavioral or mental health supports (9%), employment supports (8%), early intervention (3%) and personal care assistance (PCA) services (2%). A third of all participants reported that their family member had been on a waiting list for more than 5 years (33%). Nearly one in five (19%) had been waiting for more than ten years.

The number of people waiting for government-funded supports or services has increased since 2017, from 26% reporting that their family member was on a waitlist

compared to 35% in 2023. Fewer people reported being on the waiting list for more than five years (from 41% to 33%). Those waiting two to five years have increased from 31% to 37%, however.

Life Domains

Daily Life and Employment

School Experiences

Full inclusion in school varied across ages. Students in pre-kindergarten (29%) and kindergarten (34%) were most likely to be fully included in their classrooms. Students in middle school

Figure 9: FINDS participants were most likely to identify learning job skills, having experiences for work, and learning things that interest their family member were the most important reasons for post-secondary education.





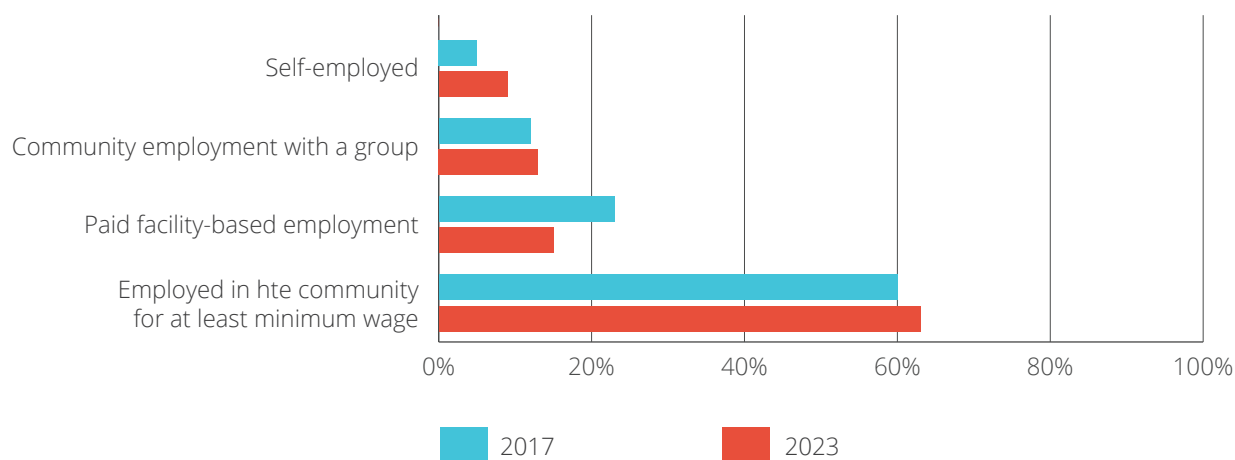
(18%) and high school (18%) were the least likely to be fully included. Middle school (28%) and high school (31%) students were also the most likely to be in schools for only students with disabilities. Across all school levels, participants were most likely to report that the person they supported was partially included in classrooms (pre-K, 29%; kindergarten, 32%; primary school, 43%; middle school, 42%; high school, 14%). Few changes have occurred in the number of parents reporting that their children were fully included in schools since 2017. Most students continue to be in partially-included settings. The number of high school students reported to be in schools only for children with disabilities has increased from 26% to 31% since 2017, however.

Post-Secondary Education

Most participants thought post-secondary education was somewhat important (32%) or very important (42%) for their family members (See Figure 8). The most common reasons that participants thought it would be necessary for their family member to go back to school include to learn new things (79%), to learn job-related skills (76%), to gain experiences and/or qualifications that will help them get a job (71%), to learn how to use transportation options (64%), or to obtain a certificate or skill (62%). All participants, except those who identified as White, were more likely than average to endorse these as reasons for the person they support to get further education. The number of participants

In central, rural, Minnesota, we are experiencing a dearth of service providers. It is really hard to find psychologists, ARMHS (Adult Rehabilitative Mental Health Services) workers, job coaches, dentists, therapists, etc., right now and that will accept Medicaid.

Figure 10: 2023 FINDS Participants Were More Likely to Report Their Employed Family Member Worked in the Community for Minimum Wage than 2017 FINDS Participants.



reporting that post-secondary education was somewhat or very important is slightly lower than in 2017 (76%).

Family Member's Work Experiences

About a quarter of participants (24%) reported that the person they supported worked for pay. Of those, 80% made at least minimum wage (See Figure 9). The average hourly wage reported was \$12.85. About 3 in 10 (31%) received employment benefits, such as insurance or a retirement plan.

Most people who were employed worked in integrated employment (63%). Fewer people worked in center-based employment (15%) or community-based group employment (13%). About 1 in 10 (9%) were self-employed. Nearly half (44%) received individual employment support, 28% received no employment support, 18% received group employment support, and 10% received other support. The most commonly reported jobs included food service (28%), janitorial work (23%), retail (21%), office work (15%), and manufacturing (13%).

The COVID employment crisis has hit our home horribly. We almost NEVER have personal aides or other support people to work with our son. The organizations we work with (through our local regional center) have horrible turnover, and because of this, our son has had an aide for a total of 10 weeks out of the last 2.5 years. The direct service providers really need to be better paid! This is a hard job that provides a service that's worth way more than minimum wage. No wonder they can't keep people in these jobs.



Since 2017, more people are reported to be working in community employment in 2023, while the number of people in paid facility employment has decreased. Self-employment has also nearly doubled between 2017 and 2023.

Of the people without paid employment, 37% were still in school. Nearly a third (32%) stayed home. Nearly half (41%) participated in unpaid community or center-based activities. For 6% of participants, COVID-19 had caused job loss or discontinuation of day program attendance for the person being supported. Participants could check more than one response, so some people supported participated in more than one activity. Nearly half (46%) did not have employment and wanted a paid job. Nearly half of those without paid employment in 2017 were still in school (49%), 16% stayed home, and 48% wanted paid employment.

Participants in the survey wanted the person they supported to participate in meaningful community activities such as volunteering (54%), participating in center-based programs (paid or unpaid activities; 44%), working in supported employment on a work crew with a job coach (37%), working in supported employment with occasional supports from a job coach (20%) or working independently (10%).

Few participants (10%) wanted their family members to be home during the day.

Community Living

Family Member's Living Arrangement

Most participants live with their family members with IDD (70%). Other living arrangements that were most commonly mentioned were living with another family member or friend (4%), living in their own home (8%), and living in a group home with six or fewer people (8%). Other types of living arrangements, such as intentional or planned communities, host or foster homes, larger group homes, institutional settings, or some other setting, were each selected by 1% of the participants as the current living arrangement of their family member. Of those who lived in their own home, 81% received supports in their home, and 18% owned their home.

Participants in 2017 were more likely to report that their family members lived by themselves or with another family member (83%) than in 2023 (74%). The number of people living in their own homes remained the same (8%), although those reported owning their own homes grew from 6% in 2017 to 18% in 2023.

Actual respite that is not a miniscule and meaningless number of hours, a real understanding of the very real burnout that happens to caregivers who provide and have been providing care to family members for a lifetime.

Growth in living arrangements included people living in an intentional or planned community (from less than 1% in 2017 to 2% in 2023). There was also growth in the number of family members reported to be in groups. In 2017, those reported living in group homes of seven or more people was less than 1% in 2017 and 3% in 2023. Group homes with six or fewer people also grew from 7% to 8% between 2017 and 2023, with most of the growth in group homes with three or fewer people.

When asked about the future, 37% thought the person they supported should continue living with them, though this varied across race and ethnicity. Caregivers identifying as AI/AN/NH/PI (31%) or White (34%) were less likely to think that their family member should continue to live with them than did those identifying as Asian (51%), Black/African-American (48%), Latine (62%), or more than one race (46%). Regarding who they should live with, most participants (41%) thought their family members should continue to live with them, and 27% thought they should live with a roommate they chose. Almost one in ten (9%) thought that living alone was the

best option, followed by living with a spouse or partner (8%), a roommate they didn't choose (8%), or a sibling or other relative (7%).

In-home Supports

Almost half (47%) of participants reported that the person they supported received in-home supports. More than a quarter (27%) received some but needed more. More than a quarter (28%) didn't receive these supports but needed them. More than half of all participants (59%) reported finding in-home supports a major problem. Participants who identified as Asian (63%), Latine (60%), and White (60%) were more likely to say that this was a major problem. In 2017, 45% of participants reported that their family members received in-home supports. About half of those (26%) needed more than they were receiving, and the other 22% reported needing it but not receiving it.

Accessibility Supports

Accessibility supports include home modifications and technology at home, work, or school that supports a person's participation in

RESPITE. HONEST to GOODNESS RESPITE so I COULD HAVE A WEEKEND FROM TIME TO TIME TO CATCH UP ON MY LIFE, MY BILLS, MY THOUGHTS - to not have to get up at 4:45 am and start the daily routine of keeping my daughter safe and entertained for the next 13 hours. I love her more than my own life. I don't really have a life anymore. Does it have to be one or the other?

I envision an Uber-type car service for transportation, so that adults with IDD can travel safely and have less anxiety instead of traveling in a medical-type Share a Ride or Access a Ride or public transportation, which is almost always late, unpredictable, and stressful.

activities. More than half (60%) of participants reported that the person they supported had accessibility supports, although 21% had these supports but needed more. Almost one in five (18%) needed them but were not receiving them. There was little change in this area from 2017.

Respite Care

Respite care services were used by 42% of the participants. A quarter (25%) reported that

they needed more than they were receiving. More than a third (37%) reported that they needed respite care but were not receiving it. Half of all participants (49%) said finding respite care was a major problem. In 2017, 39% of the participants reported using respite care, and 25% of those reported needing more respite care than they received. More than a third (36%) reported that they were not receiving respite care but needed it.



We are in a sparsely-populated, rural/suburban area. We are just far enough from dense population centers that we seem always to be outside of the range or route parameters of transportation centers.

Transportation

More than half (54%) of the participants reported that the person they supports received transportation services to go to work, a day program, medical visits, or other reasons. One in five (20%) reported needing more supports than they were currently receiving. About a quarter (23%) indicated that the person they supported needed transportation but was not receiving it. Transportation was a major problem for 28% of the participants. The number of people receiving transportation supports (54%) was the same in 2017. Fewer people (19%) reported needing it but not having it.

Out-of-home Supports

A third of participants (35%) reported that the person they supported needed residential supports outside of the family home but were not receiving them, and another 12% reported that they received some out-of-home residential supports but needed more. One in six (16%) of participants reported that their family members received out-of-home supports. More than half of all caregivers (55%) said that

finding affordable, supported living or residential supports was a major problem. In 2017, 17% of participants reported that their family members received residential support outside of the family home, and 6% reported needing more support than they were receiving. Almost a third (31%) reported needing the supports but not receiving them.

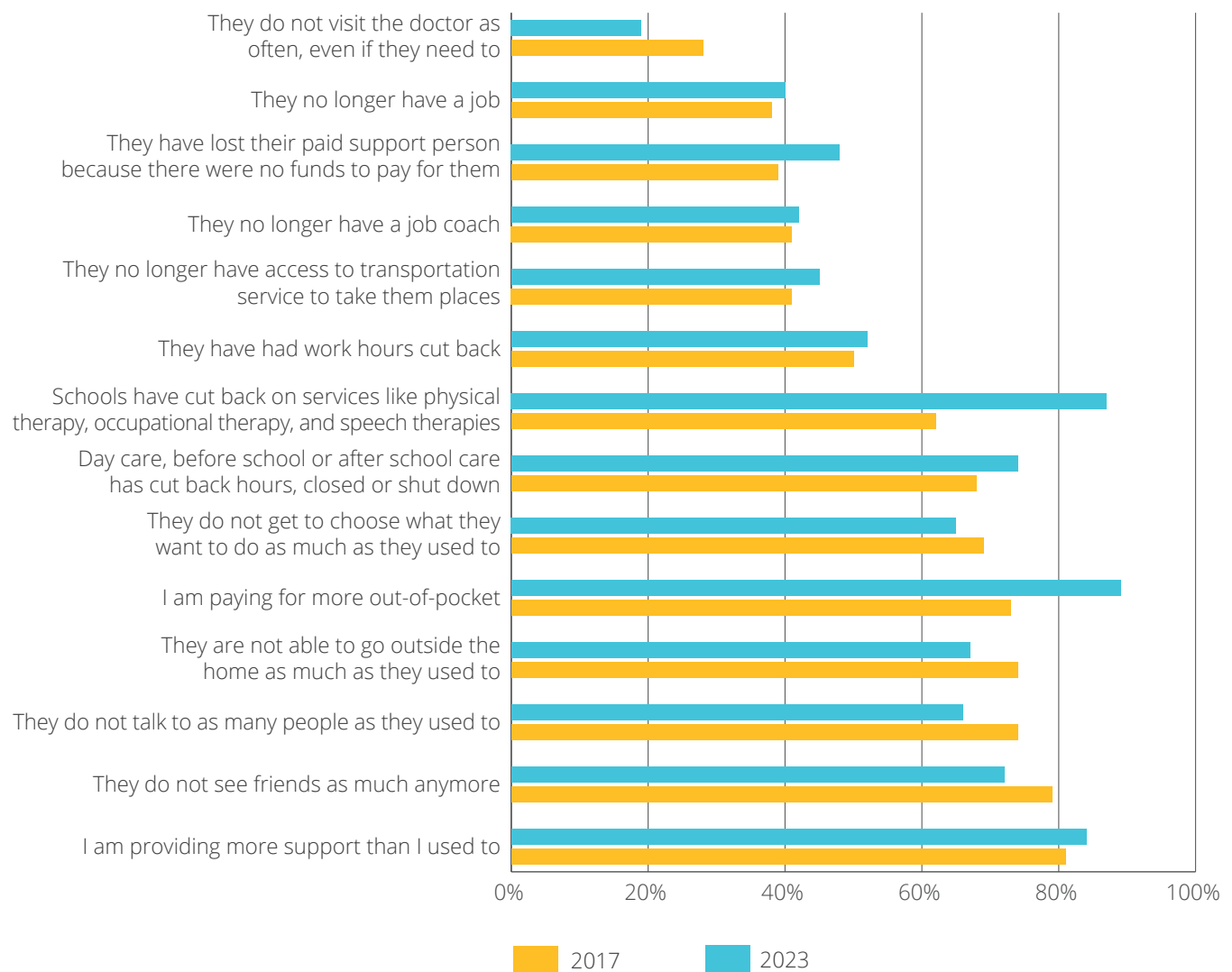
Availability of Supports

Most participants (68%) reported that the direct support workforce crisis had negatively affected the supports that their family members received. Nearly half (46%) of the participants reported that during the COVID-19 pandemic, services decreased. Another 19% reported that services started decreasing before the pandemic. A quarter (28%) thought services had stayed the same, and 7% thought that services had increased.

Services that were reduced include schools cutting back therapies such as physical, speech, and occupational therapy (62%), daycare or before- and after-school care has cut back hours or closed (68%), the participant is paying more

My son has significant mental health issues. There are very few supports and services that address these problems. Many mental health providers don't know how to treat people with IDD. And IDD services aren't set up to support his needs. In fact, State IDD services don't recognize his support needs in the assessment, so he is not eligible for services.

Figure 11: 2017 Participants Were More Likely to Report Reduced Access to Supports. 2023 Participants Were More Likely to Report Decreased Quality of Life for Their Family Members (reduced choice or social inclusion).

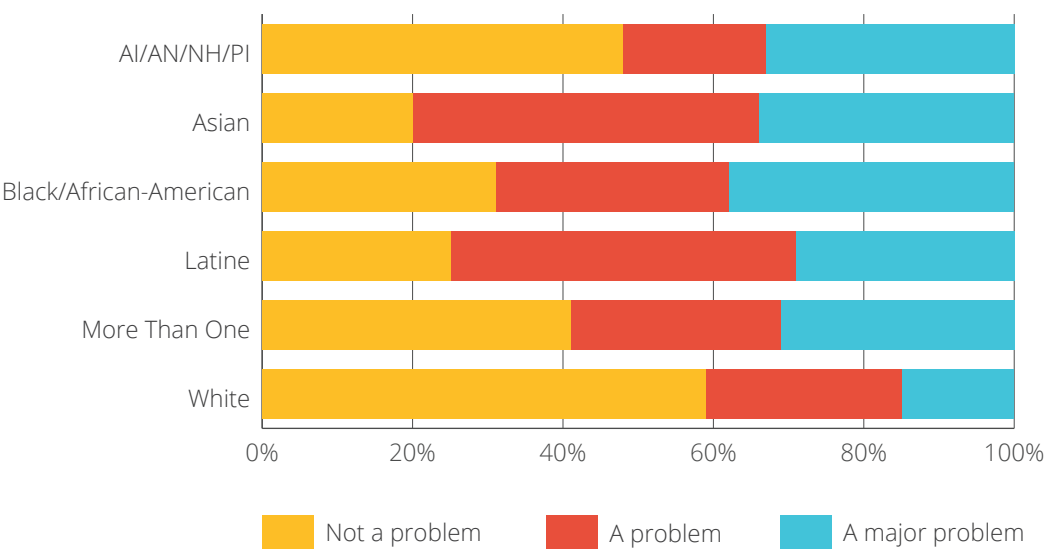


out-of-pocket (73%), the participant is providing more supports than they used to (81%), the person supported is not able to go out as much as they used to (74%) or see their friends (79%), the person is not able to talk to as many people as they used to (74%), they have less ability to choose what they want to do (74%), or they have had their work hours reduced (50%).

In 2017, FINDS participants were more likely to report that the decreasing services had affected their family in areas including reduced

school services (87%), daycare availability (74%), participant paying for services out-of-pocket (89%), and providing more supports (84%), having work hours reduced (52%), losing their job (40%), no longer having a job coach (42%), or transportation (45%; [See Figure 10](#)). Conversely, they were less likely to report that their family member was not able to get out as much as they wanted to (67%), see their friends (77%), not being able to talk to as many people (66%), having less ability to make choices (65%), or seeing their healthcare provider (19%).

Figure 12: Black or African-American Participants Were Most Likely to Report Finding Culturally Responsive Services to be a Major Problem.



Finding Culturally-Sensitive Resources

While 18% of participants noted that this was a major problem, there were significant differences across race and ethnicity. AI/AN/NH/PI (33%), Asian (34%), Black or African American (39%), Latine (29%), and people identifying more than one race (30%) all identified this a major problem while only 15% of those identifying as White did (See Figure 11).

Access to Technology

In general, participants answering questions about technology said it was easy for the person they supported to use technology to stay connected with people who are important to them (68%), attend school (67%), and do their homework (67%). More than half said it was easy for the person supported to use technology to find information to make choices (58%) or to participate in community activities (55%). Fewer than half reported that technology was easy for their family to get to where they wanted to go (46%), to find information about supports and services (44%), or to find or apply for a job (40%).

Participants were also asked to respond to

whether or not their family members had access to technology to participate in various activities. There were no reported differences across race groups in access to technology to stay connected to people who are important to them (86%), take part in community activities (74%), go where they need to go in the community (61%), make choices in their personal life (75%), and find information about services and supports (66%). There were differences in access to technology to attend school. More than 80% of participants who were Asian (86%), Latine (86%), White (83%), and those identifying more than one race (85%) reported that their family member had access. Three-fourths of Black/African-Americans (73%) and 65% of AI/AN/NH/PI participants reported access. Those in households earning more than \$60,000 per year reported greater access in all categories noted above than those with lower incomes.

Finally, caregivers were asked to what extent they agreed that having access to technology to perform these tasks would be helpful. There were no differences in any of the categories by income. There are no significant differences by race or ethnicity. Two-thirds of participants

responding agreed or strongly agreed that having access to technology would help them attend school (66%). They also agreed or strongly agreed that technology helped the person they supported to stay connected to important people (85%), to take part in community activities (78%), to use technology to get where they needed to go (69%), and for making personal choices (77%). There were differences across race and ethnicity in the other categories. People identifying as Asian (91%), Latine (85%), and having more than one race (82%) were more likely to agree or strongly agree that technology was helpful for homework. Participants identifying as AI/AI/NH/PI (65%), Black/African-American (65%), or White (65%) were less likely to think so. Somewhat similar patterns were also present for finding a job. There were differences across race and ethnicity in the other categories. People identifying as Asian (79%), Latine (85%), Black/African-American (73%), and having more than one race (73%) were more likely to agree or strongly agree. Fewer participants identifying as AI/AI/NH/PI (65%) or White (65%) agreed or strongly agreed. AI/AI/NH/PI (67%) were much less likely than the other groups to agree or strongly agree that access to technology to find information about supports and services would be helpful. Participants identifying as White (74%), Black or African-American (77%), Latine (84%), more than one race (84%), and Asian (87%) were much more likely to agree or strongly agree.

Healthy Living

Assistance with Complex Health Needs

More than half (54%) of the participants reported that the person they support needed support for complex health needs, with 25% needing more support and 18% were not receiving this support but reported a need for it.

Mental/Behavioral Health or Other Therapies

Nearly two-thirds (59%) of caregivers report that their family member received some kind of therapy, such as mental or behavioral health, physical, occupational, or speech therapy. One third (32%) reported that they needed more access to therapy. Nearly a quarter (23%) reported that the person they supported did not receive this service but needed it.

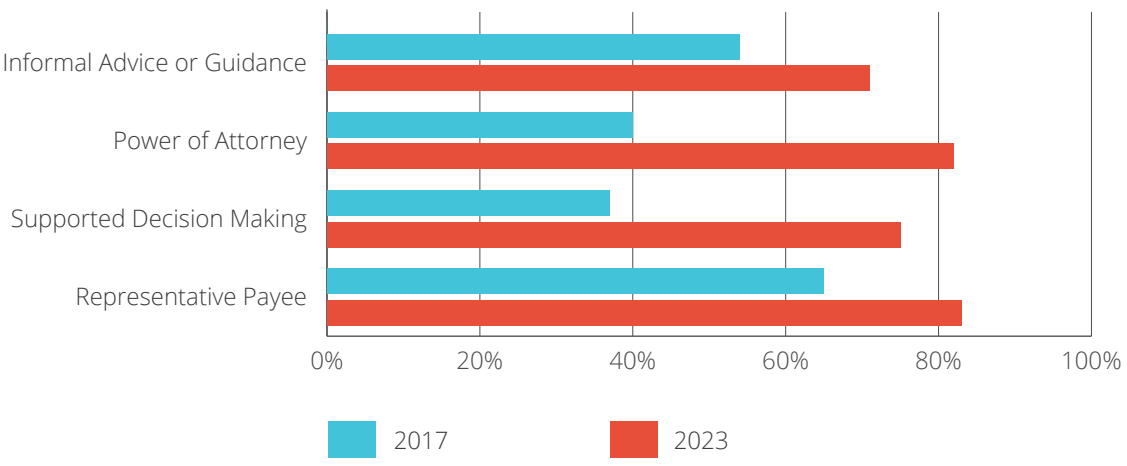
Safety and Security

Ensuring the Safety of the Person Supported

One in four (23%) of caregivers reported that ensuring the safety of the person they supported was a major problem. Caregivers who identified as Asian (34%), Latine (29%), and more than one race (28%) were more likely to identify this as a major problem. In comparison, White participants (19%) were less likely.

I would love it if when people talk about “futures planning,” they acknowledge the elephant in the room, which ISN’T financial planning and resources, but the individual’s future personal/emotional/housing support needs (basic day-to-day needs support) and assist parents in planning for that as a priority!

Figure 13: 2023 FINDS Participants Were More Likely to Have Considered Alternatives to Guardianship Than 2017 FINDS Participants



Guardianship

Six of ten participants (59%) reported that the person they supported had a court-appointed guardian or legal representative. Asian (50%), Black (50%), and Latine (51%) participants were less likely to report that their family member had a legal representative or guardian (See Figure 12). About one-third (34%) explored other options before choosing guardianship. AI/AN/ NH/PI participants (47%) and participants identified as having more than one race (43%) were likelier to explore other options. In comparison, people who identified as Asian (23%) or Latine (25%) were much less likely to explore other options. For those who explored other options, people were most likely to identify using a Representative Payee (83%) or Power of Attorney (82%), followed by Supported Decision-Making (75%) and informal advice or guidance (71%).

Fewer participants (42%) in 2017 reported that their family member had a court-appointed guardian. However, they were also less likely to report that they had considered alternatives to guardianship, including using a Representative Payee (65%) or Power of Attorney (40%), followed by Supported Decision-Making (37%) and informal advice or guidance (54%).

Legal Services

About a third of participants (30%) reported that their family member had legal services, with 15% reporting that they needed more than they received. A third (33%) reported that the person they supported needed legal services but did not have them. One participant in five (22%) noted that finding out about legal issues such as guardianship or estate planning was a major problem. Participants who identified as Asian (35%), Black or African-American (40%), or Latine (30%) were much more likely to report that accessing legal services was a major problem, as did people with household incomes of less than \$60,000 (30%). In 2017, participants reported that 14% of their family members had legal services. More than a quarter (28%) reported that they did not have them but needed them.

Planning for the Future

Almost half of the participants (48%) reported that they had a plan for supporting their family members when they could no longer do so. Participants who identified as Asian (40%) or Latine (31%) were less likely to report having a plan, as were participants with lower household incomes (40%). In 2017, 44% of participants reported not having a plan for their family member's future.



Participants were asked to identify what kind of supports they would like their family members to have when they can no longer provide supports. Nearly all participants (96%) reported wanting the person they support to have people who care about their well-being and to have friends and social activities. They also wanted their family member to have help to advocate for what they needed (93%), have a circle of supports to ensure their needs were met (93%), to live in a home they choose (92%), and to live with people they choose (92%). Participants also want their family members to be supported in making life decisions, have self-determination (92%), and have assistance with financial safety (92%). Finally, participants want their family members to have support to ensure high-quality services (92%) and be free from abuse and neglect.

Social and Spirituality

Spirituality and Religion

Slightly more than one-third (38%) of caregivers agree or strongly agree that they became more spiritual or religious due to their caregiver role. This was true for half or more participants identifying as AI/AN/NH/PI (50%) and Black or African American (51%). 2017 FINDS participants (58%) were much more likely to agree or strongly agree that they had become more spiritual or religious.

Social Connections

Three-quarters (73%) of participants agreed or strongly agreed that they enjoy helping other families and people with IDD. Half (50%) agree or strongly agree that they have found new friends, work, or interests connected to IDD. About a third (30%) agree or strongly agree that they

have closer ties to people in their community because of their role as a caregiver. However, more than half (55%) also feel lonely or isolated. Participants in the 2017 FINDS were more likely to agree or strongly agree that they enjoyed helping other families (86%), that they have found new friends (67%), or that they are more connected to their community (43%) as a result of their caregiving role. However, they were also more likely to report (64%) feeling lonely or isolated.

Advocacy and Engagement

Advocacy Services and Training

Half of the participants (50%) reported that their family members received services related to advocacy and training, with 27% needing more than they were receiving. Almost one quarter (23%) needed these services but were not receiving them. Only 32% of 2017 FINDS participants reported that their family members received advocacy services and training. Of those, 19% needed more supports. Four out of ten (40%) reported that their family member did not receive these supports, but needed them.

Advocacy by Caregivers

Two-thirds of participants (66%) reported that they agreed or strongly agreed that they were more aware of policy issues due to their role as a caregiver, and 63% are more involved in advocacy efforts or non-profit activities. More than half (55%) call their elected officials, and 82% report that they vote. 2017 FINDS participants were more likely to report that they agreed or strongly agreed that they were

aware of policy issues (88%), that they were involved in advocacy efforts or non-profit activities (82%), that they voted (95%), and they called their elected officials (73%).

Conclusion

The experiences of the participants in the 2023 FINDS show the ongoing effects of the challenges of the COVID-19 pandemic and of the direct support workforce crisis. Individuals with IDD face systemic challenges in addition to the reduction in or inability to get supports, including the lack of affordable housing and the lack of transportation, all of which limit the ability of people with IDD to live, work, recreate and fully participate in their communities. This threatens to undo decades of work done by self-advocates and their families who pushed for systemic and societal changes that support people to live a good life. The breakdown of the service system not only affects those receiving supports, it affects the whole family as family members juggle the needs of everyone. Families are doing their best to manage the disruptions caused by the seeming failure to recognize the level of the crisis and the failure to recognize the important contributions of family members who provide support. Important family roles are to love and support each other, but family caregivers may also need support to ensure that their families have economic security and that they can manage their own health and well-being. Policies that support economic security, allow for flexibility in meeting people's needs, and that are responsive to families' diverse needs are essential and urgent.

More about the Survey Method and Survey Limitations

The Research and Training Center on Community Living at the University of Minnesota, in collaboration with The Arc of the United States, conducted this survey. The Arc is a national disability organization that promotes and protects the human rights of people with intellectual and developmental disabilities (IDD) and supports their inclusion and participation in the community throughout their lifetimes. The Research and Training Center on Community Living conducts research to change national policy and practice in community living for people with intellectual and developmental disabilities.

To stop bots from spamming the survey, we added security measures throughout the survey. Bots taking surveys has become a common problem, and we want to ensure the survey results reflect families' experiences. The intended survey participant was a family member or an unrelated caregiver (such as a friend or a neighbor) who provides primary and frequent support to a person with an intellectual or developmental disability (IDD) living in the United States or its territories.

Inclusion Criteria

The criteria for study involvement were:

1. NOT having their primary relationship with an individual or individuals with IDD as a direct support professional or paid caregiver for that/those individual(s).

AND

2. In the last 12 months, providing support to any child/children under the age of 18 with IDD. This care was defined as more than the typical care required for a child their age. It included an ongoing medical condition or emotional, behavioral, or developmental concerns.

AND/OR

3. In the last 12 months, providing support to an adult relative or friend 18 years or older with intellectual or developmental disabilities to help them take care of themselves. This care was defined as helping with personal needs or household chores. It also included managing a person's finances, arranging for outside services, or regularly visiting to see how they are doing. This person need not live with the participant.

Instrumentation and Sampling

The first FINDS survey was developed in 2010. It was revised and fielded in 2017. The 2023 survey is a revised version of the 2017 survey. Focus groups, including parents and adult siblings of individuals with disabilities around the United States, were conducted via Zoom. Internally, staff from the University of Minnesota and The ARC reviewed the original instrument, incorporated items from other surveys, made recommended changes, and synthesized them into a new draft for the current FINDS. There was a limited and targeted external review of the instrument as a call for recommended modifications. Individuals who participated in this process included:

- Peter Berns
- Michele Reynolds
- Jenny Turner
- focus groups of parents and siblings

The FINDS survey was a convenience sample. Recruitment was done via social media, through The ARC's network of state and local chapters, and by sending information to other national organizations such as AUCD, Parent-to-Parent organizations, etc. Surveys were administered via Qualtrics beginning January 9, 2023. The survey was available in English, French, and Spanish; a paper/pencil version was also available in Chinese. Survey administration was open through February 10, 2023. There were 7,031 surveys in Qualtrics. 1,801 individuals did not

meet the inclusion criteria. The remainder of the “hits” to the online survey were surveys that failed Captcha, were bots, were ballot stuffers, were duplicate tests or had incomplete surveys. A total of 3,113 surveys provided usable data and this was the analytic sample.

Limitations

Online surveys can be beneficial because of the ability to reach people from a wide geographic region and they allow people to participate when it is convenient for them. One of the challenges of online surveys is they draw people with devices and access to the internet and exclude people without these resources. As is the case with the 2023 FINDS, the people who participated are, on average more likely to be White, have higher incomes, and have a higher educational level than the U.S. population as a whole. These factors should be considered when reading this report and its findings.

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