



2010 FINDS National Survey

Family and Individual Needs for Disability Supports

Technical Report Part 1 • May, 2011

Prepared for The Arc of the United States

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Collaborators: Peter Berns, Ann Cameron Caldwell, and K. Charlie Lakin

Research and Training Center on Community Living

UNIVERSITY OF MINNESOTA

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2010 FINDS NATIONAL SURVEY

Technical Report Part 1: Caregiver Survey

May 20, 2011

Prepared for The Arc of the US

By the

**University of Minnesota, Research and Training Center on Community
Living**

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A note about terminology: The Arc FINDS survey was completed with reference to people with intellectual disabilities, developmental disabilities or both intellectual and developmental disabilities. This group is referred to as people with ID/DD throughout the report. Ninety-five percent of the respondents were parents, siblings or some other relative with the remaining 5% being friends or paid caregivers. This group is referred to as family caregivers throughout the report.

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CONTENTS

Executive Summary.....	iii
Technical Report	1
The FINDS survey	1
Respondent characteristics.....	2
Characteristics of people with ID/DD	3
Education	5
Educational experiences	5
Inclusion in and satisfaction with education	6
Post secondary education.....	7
Housing and Supports.....	8
Housing	8
Support needs.....	9
Supports provided by family caregivers	10
Supports provided by a non-family member.....	11
Satisfaction with services and supports	12
Waiting lists.....	13
Sources of income for the person with ID/DD.....	14
Sources of health insurance.....	15
Supports for family caregivers	15
Challenges for family caregivers	17
Information and technology	18
Technology used	18
Technology needs	19
Employment for people with ID/DD	20
Family attitudes about employment	21
Family and caregiver outcomes	22
Physical and emotional outcomes	22
Social and family outcomes	23
Civic, social and community outcomes of caregiving.....	24
Challenges for family caregivers	24
Discussion.....	25
Similarities and Differences between FINDS Results and other similar studies.....	25
Differences in age and living arrangements	26
Differences in disability type	26
Unmet support needs	27
Caregiver/Parent needs and outcomes	27

Conclusions and Study Limitations	29
Conclusions	29
Study Limitations	30
References	33
Appendix A FINDS Technical Report Part 1 Tables	35

EXECUTIVE SUMMARY

People with intellectual and/or developmental disabilities (ID/DD) have many dreams for their future. The availability of publicly funded support to reach those dreams increased throughout much of the last half century. Between 1965 and 2009, the number of people with ID/DD living in large state institutions (the only widely available residential option other than the family home in 1965) declined from 223,590 to only 34,447. During that same period the number of children and youth in public institutions decreased from 92,000 to about 1,500. In 2009, while an estimated 1.8 million children ages 6 to 21 years with ID/DD received special education services (Larson & Lakin, 2010), only about 20,753 children and youth (ages birth to 21 years) with ID/DD lived in group settings of 4 or more individuals (Larson, Lakin, Salmi, Smith, Scott, & Webster, in press).

In 2009, 599,152 people with ID/DD received publicly funded supports while living in the home of a family member, 122,088 while living in homes of their own, and 40,967 while living in host family or foster care setting (Lakin, Larson, Salmi & Webster, 2010). In 2009 only 276,460 people with ID/DD lived in congregate care settings and 57% of those lived with six or fewer people. Most of the growth in services in the last half century has been to support people living in their own or a family home. However, between 2009 and 2011, the economic difficulties of the prolonged national recession began to slow the growth or in some places to result in actual reductions in publicly funded supports to families throughout the United States.

Family caregivers play critically important roles in supporting the well-being of people with ID/DD. This is true for family members who are the primary caregiver as well as for those whose family member with ID/DD live in their own homes or in supported residential settings. As our society continues to depend on the active engagement of family caregivers for the support of individuals with ID/DD, it is important to understand and respond to the needs of those caregivers.

In 2010 The Arc of the United States conducted a national internet survey that aimed to capture the perspectives of people with ID/DD and their family caregivers. The Family and Individual Needs for Disability Supports (FINDS) survey focused on issues including educational, housing, employment and support needs of people with ID/DD and their families. More than 5,287 family respondents participated in the survey; of these, three-quarters shared their home with a person with ID/DD. Overall, 95% of respondents were parents, siblings, children, grandparents or other relatives of a person with ID/DD.

Family caregivers report that the majority of people with ID/DD were not fully included in their schools and satisfaction with school experiences varied across age level. Family caregivers also

report a decrease in services from the schools, despite the schools being an important source of support.

People with ID/DD and their families face very real challenges to achieving their aspirations for the future. Family caregivers report that 20% of the people with ID/DD had no source of income. Overall, 62% report experiencing decreases in services and nearly a third were waiting for government funded services (32%), most for more than 5 years. They report paying for more services out of pocket (47%) and are providing more support than they used to (41%). Most family caregivers (58%) provide more than 40 hours of care per week (including 40% who provide more than 80 hours of care per week). This interferes with their work (71%) and causes physical (88%) and financial strain (81%). One-fifth of family caregivers report that someone in their family had to quit work to provide care. Nearly two-thirds of family caregivers (62%) are paying for some care out of pocket. Family caregivers also struggle to find afterschool care (80%), reliable home care providers (84%) and community-based care (82%).

Respondents reported high levels of unemployment (85% of people with ID/DD did not have a job), decreases in employment services and unmet needs in the areas of job support. For people who had jobs, family caregivers reported that the person liked what they did (82%), were satisfied with their work hours (77%), were satisfied with their wages (69%), and earned at least minimum wages (57%).

More than 40% of family caregivers reported the person with an ID/DD disability had unmet support needs during the last year for help getting outside of the home for errands or to see a doctor (48%), managing finances (46%), transportation (45%) and household management (41%). Between 28% and 38% of family caregivers reported unmet needs in the areas of self-direction (38%), job coaching or on the job support (30%), social activities (30%), and getting a job (28%).

Whether private pay or government funded, family caregivers were not satisfied with the amount of services received by the person with ID/DD. Family caregivers tended to be much more satisfied with the quality of private pay services than with government funded services.

In sum, family caregivers in 2010 reported substantial ongoing challenges to providing lifelong supports to family members with intellectual or developmental disabilities.

TECHNICAL REPORT

THE FINDS SURVEY

The web-based Family and Individual Needs for Disability Supports (FINDS) survey was launched on July 22, 2010 and was available until October 31, 2010. The FINDS survey was disseminated through public media announcements and broadly in the disability community, including the networks of The Arc, Association of University Centers on Disabilities (ACUD), the American Association on Intellectual and Developmental Disabilities (AAIDD), the American Network of Community Options and Resources (ANCOR), the National Association of Councils on Developmental Disabilities (NACDD), Self-Advocates Becoming Empowered (SABE), the National Council on Independent Living (NCIL), The Arc, Best Buddies, Easter Seals and the Autism Society of America (ASA). Thirty-eight percent of respondents came from within The Arc network, suggesting that dissemination efforts to reach a broad sample of family caregivers were successful.

There were separate surveys for family caregivers of children and adults with ID/DD and for people with ID/DD. This Technical Report Part 1 focuses only on the family caregiver survey results. Tables in the Appendix provide detailed reports of all caregiver survey results. Results for the 558 people with ID/DD who responded will be described in a separate report.

In this technical report we describe how the survey was done, and describe the results in detail. We compare results for family caregivers of people with intellectual disabilities (ID), Autism Spectrum Disorders (ASD), or other developmental disabilities (OTHER). We also compare results of the family caregiver responses that care for people with ID/DD in different age ranges and for people with different functional levels. The results are representative of the family caregivers who heard about the survey and responded. They may or may not be representative of all people with ID/DD and their family caregivers. The findings we report here by these family caregivers may not be the same as the findings we might have reported if a random sample of family caregivers had been surveyed. For example, people without Internet access may have been underrepresented.

Respondents often skipped questions leading to great variations in sample size for different questions. The number of people who responded is provided for each question and sub-group.

While separate sets of questions were created for people with ID/DD and family caregivers to complete, it was possible for people with ID/DD to respond to questions in the family section. For this report, only family caregiver responses were reported.

RESPONDENT CHARACTERISTICS

A total of 5,287 family caregivers from all 50 states responded to the FINDS Survey (See Table 1). Overall, 84% of the respondents were parents, 7% were siblings, 6% were paid family caregivers, 5% were unrelated friends, and the remaining 7% were other family members. We will refer to respondents as family caregivers or respondents in this report. Respondents ranged in age from 18 to 100 years (average age was 52.6 years). The people with ID/DD they supported ranged in age from birth to 94 years (with an average age of 23 years; See Figures 1 and 2).

Most family caregivers lived with the person with ID/DD (75%). Most were women (89%). Most were married or partnered (77%), but 19% were divorced, separated or widowed, and 4% were single never married. Overall, 10% reported annual household incomes of less than \$22,000; 33% reported incomes of \$22,000 to \$59,000, 48% reported incomes of \$60,000 to \$100,000 and 27% reported incomes of greater than \$100,000. Most had a two year college degree or more (71%). The rest reported completing some college (19%), high school (9%) or some high school (1%). Overall 54% reported a household size of three or fewer people, 28% reported having a household of four people, and 19% reported a household size of five or more.

This report compares the experiences of family caregivers of people with intellectual disabilities – ID; Autism spectrum disorders – ASD; and other developmental disabilities – OTHER. It also compares people with ID/DD by age group (0-13 years, 14-26 years, 27-39 years and more than 40), and by severity of disability (mild, moderate, severe).

Family caregivers of people with ID (63%) were more significantly more likely to be 50 years or older than family caregivers of people with ASD (34%) and family caregivers for OTHER ID/DD (12%). Family caregivers caring for people with severe ID/DD tended to be older than the other groups (57% were over the age of 50).

Family caregivers of people ages 40 and older were more likely to report being Black/African American (10%) than the other age groups.

Family caregivers of people with OTHER ID/DDs were slightly more likely to report incomes of less than \$40,000 per year than were family caregivers of people with ID or ASD (31% versus 22% and 25%, respectively).

Family caregivers' mean household size was 3.5 people. Family caregivers of people with ASD reported a somewhat larger household size (3.7 people) as did those caring for people over aged 40 (3.7 people).

Family caregivers of people with ASD were more likely to be parents (91%) than family caregivers for people with ID (82%) or OTHER ID/DDs (81%).

Slightly more family caregivers lived with a person with ASD (85%) than with people with ID (71%) or OTHER ID/DDs (75%). Family caregivers of people with mild ID/DD (78%) were more likely to live with the person they supported.

CHARACTERISTICS OF PEOPLE WITH ID/DD

DIAGNOSES

Family caregivers reported which of the following specific diagnoses the person with ID/DD had: Autism, Asperger's, Cerebral Palsy, Fetal Alcohol Syndrome, Fragile X Syndrome, Intellectual Disability, Traumatic Brain Injury, Prader-Willi Syndrome, and Spina Bifida (See Table 3). The most frequently reported diagnoses were Intellectual Disability (35%), Autism (34%) and Down syndrome (20%).

Family caregivers could report multiple diagnoses for the same person. Overall, 57% of family caregivers reported one diagnosis, 33% reported two diagnoses, and 10% reported three or more diagnoses.

Overall, 29% named one or more diagnoses that did not appear on the list. Other diagnoses listed by family caregivers included:

- Genetic syndromes such as Angelman, Cri du Chat, Williams or Rett Syndrome;
- Other types of disabilities such as ADD, pervasive developmental delay not otherwise specified (PDD-NOS), epilepsy, learning disabilities, paralysis, developmental delays, or hydrocephalus;
- Mental health diagnoses such as mood disorders, or schizophrenia;
- Vision, hearing or speech impairments; and
- Medical conditions such as cystic fibrosis, heart conditions, diabetes, PKU, multiple dystrophy or osteogenesis imperfecta.

We reviewed both the categorical and open ended responses to the diagnosis question to categorize the person with disability as having an intellectual disability, an Autism Spectrum Disorder or another type of disability.

- Individuals with a diagnosis of Intellectual Disability, Down syndrome, Fetal Alcohol Syndrome, Fragile X Syndrome, or Prader-Willi Syndrome or another diagnosis related to intellectual disability were classified as having an intellectual disability "ID."
- People with a diagnosis of Asperger's Syndrome or Autism or another related condition such as PDD-NOS were classified as having an Autism Spectrum Disorder "ASD."
- People with developmental disabilities such as Cerebral Palsy, Traumatic Brain Injury, Spina Bifida, or no specific diagnosis were classified as having an "OTHER" ID/DD.

For people with more than one diagnosis, if any of their diagnoses was an ID they classified as having ID. Those who had ASD and another disability that was not ID were classified as having an ASD. Those for whom none of their listed diagnoses were an ID or ASD were classified as having an OTHER ID/DD (See Table 3).

Overall, 62% (2,821) of people were classified as having ID, 25% (1,132) as having ASD and 13% (604) as having an OTHER ID/DD.

TYPE OF DISABILITY

A separate question asked family caregivers to identify the disability that best described the person they cared for. The most commonly reported disabilities were intellectual disability (72%), speech impairment (41%), learning disabilities (51%), mental, psychological psychiatric or emotional impairments (37%) and mobility or physical impairments (27%). Overall, 26% of family caregivers reported the person had one type of disability, 24% reported the person had two types of disability; 22% reported the person had three types of disability, and 29% reported the person had four or more types of disability.

OTHER CHARACTERISTICS

Overall, 20% of the people supported had mild ID/DD, 52% had moderate ID/DD, and 28% had severe ID/DD.

Severity of disability varied significantly across the three diagnostic groups. Those in the OTHER group were more likely to have a severe disability (37%) than those in the ID group (28%) or those in the ASD group (22%). These group differences were statistically significant.

Diagnoses more likely to be considered severe included: intellectual disability, fetal alcohol syndrome, autism, cerebral palsy, and traumatic brain injury. Diagnoses more likely to be considered moderate included Down syndrome and fetal alcohol syndrome. Asperger's syndrome was the only diagnosis most commonly considered to be a mild disability.

Of the eight specific disabilities, six were most often rated to be severe (intellectual disability, speech impairment, mental, psychological, psychiatric or emotional impairment, vision impairment, and traumatic brain injury). Learning disabilities were most often considered to be mild.

Of the people classified as having an ID diagnosis, the largest age group was those 14 to 26 years (42%). Of the people classified as having an ASD diagnosis, 30% were birth to 13 years, and 30% were 14 to 26 years. Of the people classified as having an OTHER diagnosis, 35% were 14 to 26 years, and 31% were Birth to 13 years.

EDUCATION

Family caregivers reported the highest level of education the person with ID/DD had completed, the age at which they began planning for transition to adulthood, the type of school (public, private or home school) the person with ID/DD had attended, their satisfaction with the quality of education, the extent to which the person with ID/DD was in an inclusive school environment, and their thoughts about post-secondary education.

EDUCATIONAL EXPERIENCES

For adults with ID/DD, 10% of family caregivers reported that the person had not completed high school, 42% reported that the person had received a certificate of completion, 28% reported that the person had earned a high school diploma, 14% reported that the person had earned a post-secondary certificate of completion for persons with ID/DD and 8% reported the person had completed some college or more (See Table 4).

While adults with ASD were the most likely to have earned a high school diploma (34%), they were also the most likely to have dropped out without completing high school (18%). Nearly half of adults with ID were reported to have earned a high school certificate of completion (49%) compared to about a quarter of each of the other groups. Adults with OTHER ID/DDs were much more likely to have attended and/or completed some college (21%) than those with ASD (15%) or those with ID (4%).

Adults with severe ID/DD were less likely to have completed high school (12%), earned a high school certificate of completion (44%) or to have earned a post high school certificate of completion for people with ID/DD (17%). Adults with mild ID/DD were the most likely to have earned a high school diploma (33%) or to have completed at least some college (14%).

While the average age at which family caregivers reported beginning to plan for transition to adulthood was 16.6 years, family caregivers of those in the ID and OTHER groups reported beginning to plan significantly later (17.0 years) than family caregivers of those with ASD (15.3 years).

People with ID/DD were more likely to attend public school than private or home school in each grade level (Table 5). The proportion attending public school ranged from 71% for those in preschool to 88% for those in kindergarten. Most of the students who did not attend public school were educated in a private school setting. The proportion educated in a private school ranged from 12% for kindergarten and primary school to 26% for preschool. Home schooling was used by 2% of family caregivers for children ages pre-k through primary school, and by 3% of family caregivers of middle school and high school students.

The only difference in school settings by disability type was for people with ASD who were more likely to attend a private high school. Pre-kindergarten age students with moderate or severe ID/DD were more likely to attend public school than pre-K students with mild ID/DD.

INCLUSION IN AND SATISFACTION WITH EDUCATION

Generally, family caregivers reported being satisfied with the educational experiences of the person with ID/DD (See Table 6.) Eighty percent of family caregivers reported being satisfied or very satisfied with the quality of education the person with ID/DD received in preschool but only 60 to 67% of family caregivers reported being satisfied or very satisfied with the quality of Kindergarten through high school. The proportion of family caregivers who were very dissatisfied with the quality of education increased from 8% for students in preschool to 16% for students in high school.

Respondents in the ASD group were less satisfied with the quality of kindergarten than were the other two groups. Family caregivers of people with ASD or ID were less satisfied than family caregivers of people with OTHER developmental disabilities with the quality of the high school education the person had received.

There were significant differences in caregiver satisfaction with the quality of education across all grade levels when considering severity level of the person with ID/DD. Family caregivers of people reported to have severe ID/DD were less satisfied with school experiences than family caregivers of people reported to have mild ID/DD. In the preschool age group family caregivers of people with a severe disability were also less satisfied than family caregivers of people with a mild disability with the quality of the preschool education.

Family caregivers were asked about the extent to which the person they cared for was included in school across grade levels.

- At the pre-kindergarten level, 30% of students attended a school for only students with ID/DD, 15% attended a regular school but were not included with the other children, 20% were partially included and 35% were fully included.
- At the kindergarten level, 21% of students were educated in a separate school for children with ID/DD, 13% were educated in a regular school but were not included with other children, 27% were partially included, and 39% were fully included.
- At the primary school level 22% were educated in a separate school, 10% were educated in a regular school but a segregated classroom, 40% were partially included, and 29% were fully included.
- At the middle school level, 23% were educated in a separate school, 11% attended were educated in a regular school but in a separate classroom, 37% were partially included, and 30% were fully included.

- At the high school level, 24% were educated in a separate school, 10% were educated in a separate class in a regular school; 35% were partially included in regular classes, and 32% were fully included.

From kindergarten on, students with ID were educated in significantly less inclusive environments than students with ASD or OTHER ID/DDs (See Table 7). Across all educational levels students with mild ID/DD were more likely to be included than students with moderate or severe ID/DD, and students with moderate ID/DD were more likely to be included than students with severe ID/DD.

There were several age cohort differences in the amount of inclusion at various school levels.

- At the pre-kindergarten level, family caregivers of people 40 years old or older reported significantly more school inclusion than family caregivers of people ages birth to 13 years or 14 to 26 years (possibly reflecting the lack of special pre-Kindergarten programs for the oldest cohort).
- At the kindergarten level, family caregivers of people ages 27 to 39 or 40 years or older reported more inclusion than family caregivers of people ages birth to 13 years.
- At the primary school level, family caregivers of people ages 14 to 26 reported significantly less inclusion than family caregivers of people ages 27 to 39 years or 40 years and older. Also at the primary school level family caregivers of people ages birth to 13 years reported significantly less inclusion than family caregivers of people 40 years or older.
- There were no age cohort differences in the level of inclusion at the Middle School level.
- At the high school level family caregivers of people ages 27 to 39 years reported significantly more inclusion than family caregivers of people ages 14 to 26 years.

POST SECONDARY EDUCATION

Overall, 58% of family caregivers reported it was very important that the person with ID/DD continue their education after finishing high school, or, for adults, to go back to school for post-secondary education (See Table 8); 26% felt post-secondary education was somewhat important, and 16% felt post-secondary education was not important. Family caregivers of people with ASD were most likely to report that post-secondary education was very important followed by family caregivers of people with an OTHER disability. Only half of family caregivers of people with ID felt post-secondary education was very important for that family member. Differences were also apparent across disability severity. Overall 68% of family caregivers of people with mild ID/DD thought further education was very important (68%), compared with 60% of family caregivers of people with a moderate disability, and 47% of family caregivers of people with a severe disability.

The top reasons family caregivers gave for wanting the person with ID/DD to return to school were to learn a job-related skill (73%), learn about things they were interested in (72%), and to have experiences that will help the person get a job (66%).

Purpose of further education varied across disability groups. Family caregivers of people with ASD were more likely than family caregivers of people with ID or OTHER ID/DD to report that learning job related skills was an important reason for taking post-secondary classes (80%). They were also most likely to report that having experiences that help the person to get a job (74%), having a college experience (40%), obtaining a technical degree or certification (38%) and obtaining a certificate of completion (20%) were important reasons for taking post-secondary classes. Family caregivers of people with ID were more likely than family caregivers of people with ASD or OTHER ID/DD to report that learning about things they are interested in was an important reason for taking post-secondary classes (74%). Family caregivers of people with ID or ASD were more likely than family caregivers of people with OTHER ID/DD to report that important reasons for taking post-secondary classes included fulfilling IEP plans (23%) and travel training (18% and 16%).

Important reasons for taking post-secondary classes also differed by severity of disability. Family caregivers of people with mild ID/DD (sometimes ` together with family caregivers of people with moderate ID/DD) were most likely to report as important each of the reasons except fulfilling IEP plans and travel training than family caregivers of people with severe ID/DD. Family caregivers of people with severe ID/DD were most likely to identify fulfilling IEP plans as a reason for further education. Across all severity levels at least half of the family caregivers identified either job related reasons or learning about something important as reasons for further education for people with ID/DD.

HOUSING AND SUPPORTS

HOUSING

When asked to describe the ideal living arrangement for the person with ID/DD as an adult, 43% of family caregivers thought where the person lived now was ideal, 28% thought the ideal setting would be an apartment or house owned by the person with ID/DD, and 21% thought the ideal setting would be a group home with 6 or fewer residents (See Table 9).

Family caregivers of people with ASD and OTHER ID/DDs were more likely than family caregivers of people with ID to respond that the ideal situation was for the adult with ID/DD was to own the home in which they lived. Family caregivers of people with ASD were less likely to think the person's current living arrangement was ideal.

Family caregivers of people with severe ID/DD were most likely to think the person should continue to live where they are now (51%) and least likely to think the person they care for should own their own home (13%). Family caregivers of people with mild ID/DD were the most likely to think that the person they care for should live in an apartment or house that they own (27%).

More than a third of all family caregivers (36%) reported it would be ideal for the person with ID/DD as an adult to live with roommates they chose, while 28% thought that continuing to live with parents was ideal. Living alone was identified as ideal more frequently by family caregivers of people with OTHER ID/DDs (13%) than with the ID and ASD disability groups. Family caregivers of people with mild and moderate ID/DD were most likely to report the ideal roommates would be people individual chose (39% and 38% respectively). Family caregivers of people with severe ID/DD were more likely to report the ideal roommate would be one or both parents (35%). Family caregivers of people with mild ID/DD were more likely than family caregivers of people with moderate or severe ID/DD to identify living alone as an ideal arrangement for the person as an adult (15%).

Most family caregivers did not have a plan of where the person they cared for would go if the caregiver was no longer able to provide care (62%). Family caregivers of people with ID (43%) were much more likely than family caregivers of people with ASD (26%) or family caregivers of people with OTHER ID/DDs (35%) to report having a plan.

Nearly two-thirds of all family caregivers worry that the person they care for might have to go somewhere they don't want to live. Family caregivers of people with OTHER ID/DDs were the least likely to report this as a concern (53%). Family caregivers of people with moderate or severe ID/DD were more likely than family caregivers of people with mild ID/DD to report worrying about the person with ID/DD having to live somewhere they do not wish to live (66% and 64% vs. 47%).

Relatively few family caregivers, 17%, reported not having thought about future housing options. Family caregivers of people with ASD and OTHER ID/DDs (26% and 24% respectively) were more likely to report that they haven't thought about the future than family caregivers of people with ID (17%).

SUPPORT NEEDS

More than 40% of all family caregivers reported the person with ID/DD had unmet support needs during the last year for help getting outside of the home for errands or to see a doctor (48%), managing finances (46%), transportation (45%) and household management (41%). Between 28% and 38% of family caregivers reported unmet needs in the areas of self-direction

(38%), job coaching or on the job support (30%), social activities (30%), and getting a job (28%; See Table 10).

People with ASD were less likely to have unmet support needs than people with ID or OTHER ID/DDs in all eight areas. People with severe ID/DD were more likely to have unmet needs for support in managing finances and transportation (57% vs. 42% for those with OTHER ID/DDs, and 46% for those with ID). People with mild ID/DD were more likely to report having unmet needs for support in each of the other seven areas.

Overall, 39% of family caregivers reported no unmet needs, 43% reported between one and four unmet needs, and 19% reported having five or more unmet needs during the last year. On average family caregivers reported the person with ID/DD as having 2.1 unmet needs. Family caregivers of people with ID or OTHER ID/DDs reported more unmet needs than family caregivers of people with ASD (2.3 and 2.4 vs. 1.4 respectively). There were no differences in the number of unmet needs by age group. Interestingly, family caregivers who reported the person with ID/DD had a mild disability reported significantly more unmet needs on average (2.5) than family caregivers of people with moderate (2.0) or severe (2.0) ID/DD.

SUPPORTS PROVIDED BY FAMILY CAREGIVERS

Family caregivers provided a wide range of supports to the people with ID/DD (see Table 11a). Overall, 86% reported providing emotional reassurance, 84% reported providing transportation, and 80% reported cooking, doing laundry or cleaning the house. Between 70 and 79% of family caregivers reported providing support with financial affairs (78%), social arrangements (77%), monitoring outside services (76%), home maintenance (72%), or recreational activities (71%). Seventy-two percent of all family caregivers reported providing direct financial support to the person with ID/DD. The majority of family caregivers also reported providing support for medication administration (69%), personal care (61%), and coordinating community or religious activities (58%).

There were no significant differences across disability type in the proportion of family caregivers who reported providing care or support to people with ID/DD. Family caregivers of people with mild ID/DD were less likely to provide support with home maintenance (73%) than family caregivers of people with moderate ID/DD (75%). Family caregivers of children 13 years or younger were significantly less likely to report providing support by receiving support in these areas than were other age groups. However they were more likely to provide other types of supports (43% vs. 0% for the other age groups). There were no age related differences in the proportion who reported providing financial support or sign language interpretation.

On average family caregivers reported providing 9.1 of the 13 listed supports to the person with ID/DD. Overall 46% of family caregivers reported providing 11 to 13 of the listed supports, 37%

reported providing 6 to 10 of the listed supports, and 17% reported providing 1 to five of the supports.

Family caregivers of people with ASD reported providing support in significantly more areas than family caregivers of people with ID or OTHER ID/DDs (9.5 areas vs. 9.0 and 8.8 respectively). The number of supports provided did not differ by age group. Family caregivers of people with severe ID/DD reported providing an average of 9.6 types of support, family caregivers of people with moderate ID/DD reported providing an average of 9.2 types of support and family caregivers of people with mild ID/DD reported providing a total of 8.1 types of support to the person with ID/DD. Each of these groups is significantly different than each of the others.

Overall, 40% family caregivers reported providing more than 80 hours of support per week to the person with ID/DD. An additional 18% reported providing 41 to 80 hours of support, and 21% reported providing 15 to 40 hours of support per week.

Family caregivers of people with ASD were the most likely to report providing 80 or more hours of support per week (45%) and least likely to report providing fewer than 15 hours of support per week (15%). While more than 30% of family caregivers in each group reported providing 80 hours of support per week to the person with ID/DD, 50% of family caregivers of people with severe ID/DD reported doing so.

Overall 18% of family caregivers reported that one or more family members were paid to provide supports to the person with ID/DD. Funds to pay for that support were provided primarily by the Medicaid HCBS Waiver program (52%) or from family or individual savings or income (40%). Other sources were noted for 24% of family caregivers, and special needs trusts and private insurance were each noted for 2% of family caregivers. There was relatively little variation in funding source by disability type, level or age. Family caregivers of people with OTHER ID/DDs were more likely to have been paid through the Medicaid HCBS Waiver program (40%), while family caregivers of people with ASD were most likely to have been paid from family or personal sources (51%), most notably from the personal income of the parent, family member or other caregiver (40%). People with severe ID/DD were more likely to have reported getting supports from a family member paid through the HCBS Waiver program (59%), while people with mild ID/DD were most likely to have received supports from a family member paid out of personal or family sources (56%), most often the personal income of a parent, family member or other caregiver.

SUPPORTS PROVIDED BY A NON-FAMILY MEMBER

Most family caregivers (62%) reported that someone outside the family was paid to provide supports to the person with ID/DD during the previous month. Overall, 19% of family caregivers

reported that someone outside the family was paid less than \$250, 23% reported someone was paid \$250 to \$999, and 21% reported that someone was paid \$1,000 or more in a typical month to provide supports to the person with ID/DD (See Table 11b).

Supports provided by someone other than a family member were paid for in a variety of ways and many family caregivers reported two or more sources of payment. Overall, 52% of family caregivers paid for care out of their own income, 50% of family caregivers reported that services were paid by the Medicaid Home and Community Based Waiver program, 21% reported that supports were paid for out of the person with ID/DD's income, and 12% reported that supports were paid for out of personal savings of a parent, family member or other caregiver. Private insurance paid the costs of care from a non-family member for 8% of the family caregivers, the person with ID/DD's savings were used to pay for this care 3% of the time, and a special needs trust paid for non-family member supports 3% of the time.

Family caregivers of people with ASD were more likely to report paying for care given by non-family members out of their personal income (67%), more likely to report using the personal savings of a caregiver (17%) and less likely to use HCBS waiver funds (36%) than family caregivers of people with ID or OTHER ID/DD. Family caregivers of people with ID and OTHER ID/DDs reported the most common source of funds to be the HCBS waiver program (54% and 55% respectively), followed closely by personal income of the family member or other caregiver (47% and 47%). Family caregivers of people with ID were more likely than those of people with ASD or OTHER ID/DDs to pay for some of their care out of their own personal income (24% vs. 16% and 17%). Family caregivers of people with ID or OTHER ID/DDs were more likely to report using special needs trusts to pay for supports provided by non-family members than family caregivers of people with ASD (4% vs. 1%).

Family caregivers supporting people with mild or moderate ID/DD were more likely to report paying for care out of the personal income of parents, family members or other family caregivers (71% and 57% respectively) than family caregivers supporting people with severe ID/DD (65%). Family caregivers supporting people with severe ID/DD reported having an HCBS waiver (58%).

Family caregivers supporting children ages 0-13 were more likely to be paying for services out of their own incomes (59%) and family caregivers supporting people with ID/DD ages 27 to 39 years were most likely to report receiving services from non-family members paid for by the Medicaid HCBS Waiver program.

SATISFACTION WITH SERVICES AND SUPPORTS

Family caregivers were asked how satisfied they were with the quality and amounts of government-funded and private pay supports (Table 12). About half of family caregivers

reported being *dissatisfied* with the quality of government funded employment services (57% dissatisfied), housing services (50%) and therapy services (49%). Family caregivers supporting people with ASD were significantly less satisfied with the quality of government funded personal supports (56% dissatisfied), housing (65% dissatisfied), transportation (55%), or employment services (69% dissatisfied) than were the ID and OTHER ID/DD groups.

The majority of all family caregivers (between 68% and 79% depending on the type of service) were dissatisfied with the amount of government funded services received by the person with ID/DD. Overall, family caregivers were most dissatisfied with the amount of therapy services (79% were dissatisfied), respite care (78%), and housing supports (77%). Amongst family caregivers whose member was 18 years or older, 77% were dissatisfied with the amount of government funded employment services available to the person with ID/DD. Family caregivers supporting people with ASD were more likely to be dissatisfied with the amount of the listed services with the difference being statistically significant for employment supports (86% were dissatisfied), housing supports (83% were dissatisfied), therapy services (83% were dissatisfied), and personal support (80% were dissatisfied).

More family caregivers reported being satisfied with the *quality* of private pay services. Overall 70% were satisfied with the quality of personal support services paid for with private funds, 66% were satisfied with the quality of therapy services, 64% were satisfied with the quality of transportation services, 61% were satisfied with the quality of private pay respite care, and 60% were satisfied with the quality of privately paid housing supports. More than half (53%) of family caregivers reported being dissatisfied with the quality of privately paid employment supports. Family caregivers supporting people with ASD were significantly less satisfied with the quality transportation and employment services paid for from private funds and were significantly less satisfied with the amount of housing supports and employment supports paid for by private funds.

WAITING LISTS

Overall, 32% of the family caregivers reported that they were waiting for government funded services (See Table 13). While there were no statistically significant differences in the proportion waiting for the different age groups, the proportion of family caregivers saying they were waiting was significantly higher for those whose family member had ID (32%) or ASD (37%) than for those whose family member had an OTHER ID/DD (26%). Similarly more family caregivers supporting people with moderate (34%) or severe (32%) ID/DD reported waiting than those of people with mild (27%) ID/DD. Overall, 7% of family caregivers report that they don't know how to get on a waiting list for supports. Family caregivers supporting people with ASD were more likely to report (9%) they did not know how to get on a waiting list than family caregivers supporting people with ID or OTHER ID/DDs.

Family caregivers report waiting for government funded services for an average of 5.3 years. Overall, 17% of family caregivers had been waiting for 1 year or less, 39% had been waiting between 2 and 4 years, and 44% had been waiting five years or longer. Family caregivers supporting people with ID had been waiting longer (5.6 years) than those supporting people with ASD (4.6 years). Family caregivers most often were waiting for personal support assistance (14%); respite care (11%) and community based housing (10%).

More family caregivers supporting people with ID reported waiting for community-based housing (12%), employment supports (8%), and transportation (6%) than the other two disability groups. More family caregivers supporting people with ASD or ID reported waiting for personal support assistance (15% and 14% respectively). Family caregivers supporting people with ASD were more likely to be waiting for respite care (13%), and therapy services (14%) than family caregivers supporting people with ID or OTHER ID/DD.

Family caregivers supporting people with mild ID/DD were the least likely to report waiting for government funded services in all areas except employment supports while family caregivers supporting people with moderate ID/DD were the most likely to report waiting for all listed services except respite care.

SOURCES OF INCOME FOR THE PERSON WITH ID/DD

Family caregivers were asked to identify all sources of personal income for the person with ID/DD. Here we report income sources for people with ID/DD ages 18 and older. Overall, the most common sources of income for adults with ID/DD were Supplemental Security Income (SSI; 33%), their family (30%), and Social Security Disability or Retirement Insurance (OASDI) (21%). Overall 25% of family caregivers reported the adults with ID/DD had no source of personal income.

Family caregivers supporting adults with ASD were more likely to report the person had no source of income (38%), and were significantly less likely to report the person had income from the family (28%), SSI (24%), employment (12%) or OASDI (11%).

Family caregivers supporting people with mild ID/DD were more likely to report that the person had no source of personal income (31%), to get income from family members (31%), and to have employment income (26% compared with 21% for those with moderate ID/DD and 10% for people with severe ID/DD).

SOURCES OF HEALTH INSURANCE

Family caregivers reported on six possible sources of health insurance for the person with ID/DD. Overall the most commonly reported sources of health insurance for the person with ID/DD were Medicaid or a state program for people with low incomes (60%), insurance through family members (59%), and Medicare (24%; See Table 14b).

Family caregivers of people with ASD were much more likely to report using health insurance through a family member's employer (72%), and were much less likely to report using Medicaid (45%), Medicare (11%), or insurance through the person with ID/DD's employer (0%).

Family caregivers who supported people with severe ID/DD were much more likely to report using Medicaid (73%). Family caregivers supporting people with mild ID/DD were more likely to report health insurance through a family member's employer (64%), the person with ID/DD's employer (3%), or having no health insurance (2%). Family caregivers supporting children and youth ages 14 to 26 years were significantly more likely to report using Medicaid (64%) than family caregivers supporting people 40 years or older (56%).

Overall, 69% of people with ID/DD received either Medicare or Medicaid or both, 62% had health insurance through their family member, and 32% had at least one public and at least one private source of insurance. People with ID were significantly more likely to have both publicly and privately funded sources of health insurance (34%) than those with ASD or OTHER ID/DDs (27% and 32% respectively). People with severe ID/DD were also more likely to have both public and private sources for health insurance (39%) than people with mild or moderate ID/DD (24% and 31% respectively). There were no significant differences in the proportion of people with both private and publicly funded insurance by age.

SUPPORTS FOR FAMILY CAREGIVERS

Services and supports rated as important to family caregivers were advocacy services at the local level (74%), recreation supports (62%), information about services available in my state (62%), and information about local services and programs (59%; see Table 14a). More than half of family caregivers said it was important to have information about family support services (54%), advocacy services to help me understand our rights (53%), physical activities and sports programs (53%), information about new technologies (52%), special needs trusts or financial planning (51%), inclusive community programs (50%), legal services (50%) and respite services (50%).

Of the services rated as important by 50% or more of family caregivers, those supporting people with ID were more likely to value local advocacy services to get supports and transportation services. Family caregivers supporting people with OTHER ID/DDs were more likely to rate as important information about new technologies. Family caregivers supporting

people with ASD were most likely to rate as important local advocacy services to get supports, recreation services, information about local services and programs, information about family support services, advocacy services to understand our rights, special needs trusts or financial planning, inclusive community programs, and respite services. With the exception of information about special needs trusts and financial planning (50%), self-advocacy programs (49%), independent living services (47%), and internship programs at local businesses (36%), family caregivers supporting people with mild ID/DD were less likely to report these supports were important than family caregivers supporting people with moderate or severe ID/DD.

More than 50% of family caregivers supporting people with ASD rated as important help navigating services (53%), information about benefits counseling (54%), therapeutic services (OT, PT, Speech; 54%), and self-advocacy programs (50%). More than 50% of family caregivers supporting people with OTHER ID/DDs also rated as important therapeutic services (OT, PT, speech; 52%).

INFORMATION AND REFERRAL

Most family caregivers reported being connected to others in the disability community (76%), knowing how to find out if the person with ID/DD could get disability benefits (70%), knowing whether or not the person with ID/DD can get disability benefits (69%), knowing where to get help for what the person with ID/DD needs (56%), and knowing how to get transportation supports (54%; See Table 17). That said, many were not connected or did not know how to get these supports.

Family caregivers supporting people with ID or OTHER ID/DDs were more like to know these things than family caregivers supporting those with ASD. Family caregivers supporting people with severe ID/DD were more likely to report that they know how to find out about getting disability benefits, and to know whether or not the person with ID/DD can get disability benefits than family caregivers supporting people with mild or moderate ID/DD. Family caregivers supporting the oldest people with ID/DD (those 40 years and older) were significantly less likely than family caregivers supporting younger people with ID/DD to report knowing how to find out if the person can get disability benefits.

Most family caregivers did not believe that they had enough help planning for the future (65%), and most reported not having enough information to make good decisions about housing options (59%). Family caregivers supporting people with ASD were the least likely to agree that they knew how to access information and assistance when needed. Family caregivers supporting people with mild ID/DD were more likely to report having information about housing options and in planning for the future.

SOURCES OF SUPPORT FROM ORGANIZATIONS

The most commonly used local disability specific support services were provided by a local chapter of The Arc (38%) or another local community-based disability organization (31%; see Table 15). In addition, 31% of family caregivers reported getting supports from their school. The most common state or national organizations used for supports were Special Olympics (25%), and a state Developmental ID/DD Council (12%). Overall 17% of family caregivers reported that they were not receiving services from any of the listed organization types.

Types of services used varied across disability type. Family caregivers supporting people with ID were more likely to get supports from a local community-based disability organization (35%), Special Olympics (31%), People First/ Self Advocates Becoming Empowered (5%), action clubs (4%) and Best Buddies (4%).

Family caregivers supporting people with ASD were more likely to report using services from their school (45%), a local Chapter of The Arc (34%), the Autism Society of America (28%), a local therapeutic agency (16%), or a local self-advocacy group (15%), than were the other groups.

Family caregivers supporting people with OTHER ID/DDs were more likely to report using a local chapter of The Arc (38%), or a Center for Independent Living (5%). They were also most likely to say they did not use any services listed (25%).

There were only a few differences in the types of support used by severity of disability. Family caregivers who supported a person with moderate or severe ID/DD were more likely than those with mild ID/DD to report accessing a local chapter of The Arc. Family caregivers of people with a severe disability were more likely to report accessing the state Developmental Disabilities Council, or a local United Cerebral Palsy agency. Family caregivers of people with moderate ID/DD were more likely to use one or more of these organizations than those with mild or severe ID/DD.

CHALLENGES FOR FAMILY CAREGIVERS

Sixty-two percent of family caregivers reported that services in their communities were decreasing while 31% reported services were staying about the same (Table 16). The proportion of family caregivers reporting that services were decreasing was larger for those supporting people with severe ID/DD (70%) than for those supporting people with moderate (60%) or mild (54%) ID/DD.

Nearly half of the family caregivers were paying for services out of pocket (47%), and 43% reported having to provide more supports. Twenty percent of family caregivers reported that someone in the family had to quit their job to support the person with ID/DD. Family caregivers

supporting people with ASD were more likely to report paying for services out of pocket (55%), and to report that as a result of decreasing services someone in the family had to quit their job to support the person with ID/DD (28%). Family caregivers supporting people with moderate or severe ID/DD were providing more support and were more likely to report having someone in the family quit their job to provide that support than family caregivers supporting people with mild ID/DD.

IMPACT OF SERVICE CUTS FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Decreasing supports were reported to result in the person with ID/DD losing services such as PT, OT and Speech provided by schools (43%), not being able to go outside the home as much (29%), not seeing friends as much (24%), not making as many choices (23%), and not talking to as many people (18%) as they had in the past.

Family caregivers supporting people with ASD were more likely to report that schools cut back on therapies (55%). Family caregivers supporting people with ID or OTHER ID/DDs were more likely to report that the person with ID/DD did not go outside as often, didn't see friends as often, didn't choose what they did as often, and that they didn't have transportation. Family caregivers supporting people with ID were more likely to report that they person had their hours cut at their job (12%), or that they no longer have a job coach (8%). Family caregivers supporting people with OTHER ID/DDs reported that the person no longer had a job (11%).

Family caregivers supporting people with severe ID/DD were more likely to report that the person could not leave the home as often (41%), and that they didn't see their friends as often (28%) than family caregivers supporting people with mild or moderate ID/DD. Family caregivers supporting people with mild or moderate ID/DD were more likely to report the person's hours at work were cut, that the person lost their job, or that they no longer have a job coach.

INFORMATION AND TECHNOLOGY

TECHNOLOGY USED

Overall the most common types of technology used by the person with ID/DD were a cell phone (47%), computer/software (32%), wheelchair, cart or scooter (28%), and knee or ankle braces or orthotics (22%; See Table 18a). Between 15% and 20% of family caregivers reported using a vehicle big enough to safely transport a wheelchair or scooter (17%); exercise equipment (16%), or a ramp at home (15%).

Family caregivers supporting people with ASD were more likely than the other family caregivers to report using cell phones (52%), computer/software (40%), picture communication software (15%), and portable GPS devices (6%). Family caregivers supporting people with ID and family

caregivers supporting people with OTHER ID/DDs were more likely than family caregivers supporting people with ASD to report using vision assistance and hearing assistance or aids. Significantly more family caregivers supporting people with OTHER ID/DDs reported using the other technologies or assistive devices than family caregivers supporting people with ID or ASD. The most often used technologies reported by family caregivers supporting people with OTHER ID/DDs were wheelchair, cart or scooter (61%), vehicle large enough to safely transport a wheelchair (40%), a ramp at home (40%); knee or ankle braces or orthotics (35%) and home modifications for accessibility (30%).

Family caregivers supporting people with severe ID/DD were more likely to report having almost all assistive devices with the exception of cell phones which people with mild ID/DD were more likely to have. The only age difference was family caregivers of adults ages 40 and older were more likely to report having portable GPS than family caregivers of younger adults (8% vs. 2%).

TECHNOLOGY NEEDS

Overall 35% of family caregivers reported unmet needs for special equipment, technology or other assistive devices (Table 18b). Family caregivers supporting people with OTHER ID/DDs (49%) and with severe ID/DD (55%) were much more likely to report unmet needs in this area.

Overall, the most commonly reported unmet needs for special equipment or technology were computers/software (40%), exercise equipment (38%), picture communication software (35%), smart home technology (33%), audio books (27%), and communication board devices (25%).

Family caregivers supporting people with ID or ASD were more likely than family caregivers supporting people with OTHER ID/DDs to report unmet needs for picture communication software, and communication board devices. Family caregivers supporting people with ASD were more likely to report needing computers/software, and portable GPS systems. Family caregivers supporting people with OTHER ID/DDs were the most likely to report needing mobility devices such as wheelchairs and walkers and modifications for accessibility such as ramps, home modifications, lifts and accessible vehicles.

Family caregivers supporting people with severe ID/DD reported needing communication devices such as picture communication boards, mobility assistive devices and home modifications including smart home technology more frequently than the other groups. Family caregivers supporting people with mild and moderate ID/DD were more likely to report needing GPS devices and cell phones.

Family caregivers supporting people over 40 were more likely to report needing exercise equipment, picture communication devices, video communications, lifts, vision assistance and prosthetics.

The primary reason family caregivers reported for not having needed technology was that they couldn't afford it (67%), followed by insurance declining it (16%) and never trying to get it (16%). Ten percent of family caregivers reported not knowing where to get assistive technology. Family caregivers supporting people with ASD were more likely than family caregivers supporting people with ID or OTHER ID/DDs to report that they couldn't afford needed technology (75%). Family caregivers supporting people with OTHER ID/DDs were most likely to report insurance declining to cover it (26%) or that it was on order but hadn't arrived (6%).

Family caregivers supporting people with severe ID/DD were more likely to report that they didn't have technology because insurance declined it (22%), they were on a waiting list for it (6%), they had used it, but it didn't help (5%) or some other reason (16%). Family caregivers supporting children 0-13 were most likely to report not being able to afford equipment (75%), while family caregivers supporting people 40 years and older were most likely to report that they weren't comfortable using the devices/equipment (8%).

EMPLOYMENT FOR PEOPLE WITH ID/DD

Overall, 85% of family caregivers reported that the adult with ID/DD did not have a job (See Table 19a). For those that were employed, the proportion with a job did not differ by disability type or level, but people 18 to 26 years were significantly more likely to be employed than people ages 40 and older (18% versus 13%). Overall, 7% of family caregivers said the person they supported had a regular job in the community, 6% said the person worked in a sheltered workshop, 3% said the person with ID/DD worked in an enclave made up of only people with ID/DD and 1% said the person with ID/DD was self-employed.

For those reported to be working, the most commonly reported types of work were piecework, assembly, packaging and shipping (32%), facility maintenance, janitorial or cleaning (19%), office work (16%) and food preparation or service (14%). Family caregivers supporting people with ID were more likely to report the person worked in child care than families of those with ASD or OTHER ID/DDs. Family caregivers supporting people with ASD were more likely to report that the person worked doing piece work (42%). Family caregivers supporting people with OTHER ID/DDs were more likely than family caregivers supporting those with ID or ASD to report that the person worked in food preparation or bussing tables (24%) or animal care (5%).

For the 15% of adults with ID/DD who had a job, only 48% family caregivers reported that person received a competitive wage. More than half of all family caregivers reported that the

person liked what they do at their job (82%), are satisfied with their hours (78%), are satisfied with their wages (69%) and earn at least minimum wages at their job (57%). Fewer family caregivers reported that the person with ID/DD set and pursued employment goals (49%), got job training when they needed it (48%), got help finding and keeping their job when needed (48%), earned benefits from their employer similar to those earned by employees without ID/DD (32%), or could advance into a position with more responsibilities (28%).

FAMILY ATTITUDES ABOUT EMPLOYMENT

Family caregivers overwhelmingly thought that people with ID/DD should be paid at least minimum wage for their work (82%). There were no differences across disability types, severity levels or age groups (Table 19b).

Overall family caregivers were most likely to prefer that the person with ID/DD work in a regular job in the community (62%). Overall, 19% preferred a sheltered workshop, 12% preferred an enclave setting and 7% preferred self-employment. While family caregivers supporting all groups preferred a regular community job most and self-employment least, family's preferred employment location varied by disability type and age of the person. Family caregivers supporting people with ID were somewhat more likely to prefer a regular job in the community (65%), family caregivers supporting people with ASD were slightly more likely to prefer a sheltered workshop (21%), and family caregivers supporting people with OTHER ID/DDs were slightly more likely to prefer an enclave setting. Family caregivers supporting the youngest group of people with ID/DD were more likely to prefer a regular job in the community (66%) or self-employment (8%). Family caregivers supporting people ages 14 to 26 years were somewhat more likely to prefer an enclave (14%) or self-employment (8%). Family caregivers supporting the older groups (27-39 and 40+) were somewhat less likely to prefer a regular community job (62% and 59% respectively) and somewhat more likely to prefer a sheltered workshop (21% and 24% respectively).

Family caregivers reported whether the person with ID/DD who had worked in various settings is/was satisfied with the work setting and type of work. More than 80% of family caregivers reported that people with ID/DD who had worked in a regular community job (84%) or were self-employed (81%) were satisfied with the setting in which they worked. Fewer family caregivers reported people with ID/DD who had worked in enclave settings (74%) or sheltered workshop (68%) were satisfied with their work setting.

Family caregivers were somewhat less likely to report that the person with ID/DD had been satisfied with the type of work they had done in regular community jobs (69%), self-employment (79%), enclave settings (65%), or sheltered workshops (42%).

Family caregivers reported that people who had worked in sheltered workshops were least satisfied with both the work setting and the type of work. However, this was the second most preferred work setting for family caregivers. Very few family caregivers preferred self-employment for the person (7%) but family caregivers supporting people who had been self-employed were highly satisfied with their work setting (81%), and were most satisfied with the type of work (79%) compared to the three other work settings.

FAMILY AND CAREGIVER OUTCOMES

PHYSICAL AND EMOTIONAL OUTCOMES

Most family caregivers reported negative physical or emotional outcomes associated with care giving (See Table 20). The most common outcomes included physical strain or fatigue (34% reported feeling this most of the time; 54% reported feeling this sometimes); financial strain (35% most of the time, 46% sometimes); emotional upset or guilt (22% most of the time, 59% sometimes); and stress in close personal relationships (25% most of the time, 52% sometimes). More than half of family caregivers reported that they sometimes or most of the time experienced feeling underappreciated, reluctance to ask for help, personal health issues, interference with work, loneliness, and concerns about how to support and explain to the person with ID/DD's siblings.

There were many differences in the frequency with which care givers reported these outcomes by disability type, level, and age category. Family caregivers supporting people with ID or OTHER ID/DDs were more likely than family caregivers supporting people with ASD to report physical strain or fatigue. Family caregivers supporting people with ASD or OTHER ID/DDs were more likely to report feeling underappreciated than family caregivers supporting people with ID. For all other items, family caregivers supporting people with ASD were more likely to report these physical or emotional outcomes.

For almost all of the physical and emotional outcomes, family caregivers supporting people with severe ID/DD reported negative effects more often than family caregivers supporting people with mild or moderate ID/DD. Family caregivers supporting people with moderate ID/DD were as likely as those with severe ID/DD to report emotional upset or guilt. Family caregivers supporting people ages 0-13 and 27-39 were reported financial strain more often than family caregivers supporting people ages 14 to 26 and family caregivers supporting people ages 40 years and older.

Only 16% of family caregivers reported excellent health, while 54% reported good health, 26% reported fair health, and 4% reported poor health. Family caregivers of people with ID reported being in poorer health on average than family caregivers of people with ASD or OTHER ID/DDs.

Family caregivers supporting people with mild ID/DD were more likely than those of people with moderate or severe ID/DD to report being in poorer health.

Overall, 51% of family caregivers reported being somewhat stressed, 30% reported being very stressed, and 12% reported being extremely stressed. Family caregivers of people with ASD reported more stress than family caregivers supporting people with ID or OTHER ID/DDs. Family caregivers supporting people with severe ID/DD reported more stress than those with mild or moderate ID/DD and family caregivers supporting people with moderate ID/DD reported more stress than family caregivers supporting people with mild ID/DD. Family caregivers supporting those ages 14 to 26 reported a bit less stress than family caregivers supporting people in the other age groups.

SOCIAL AND FAMILY OUTCOMES

Most family caregivers (63%) agreed or strongly agreed they did not have enough time for themselves because of care giving responsibilities (Table 21). Nearly half of care givers reported having more care giving responsibilities than they could handle comfortably (46%), and often feeling guilty about care giving to their child with ID/DD versus other children in the family (47%).

About half of family caregivers reported doing a good job of meeting work, family and personal responsibilities (57%) and feeling in control of important things in their life (57%). However more than half of the family caregivers reported not getting a restful night's sleep (54%), experiencing adverse effects on their marriage (58%), not having an active enjoyable social life (61%), not being able to pursue work/career goals to the fullest extent (67%), not having a healthy retirement account (73%), and having difficulty finding afterschool care for their child with ID/DD (90%).

Family caregivers supporting people with different types and levels of ID/DD experienced different levels of negative social and family outcomes. For all of the outcomes except afterschool child care, family caregivers supporting people with ASD were more likely to report negative outcomes than family caregivers supporting people with ID or OTHER ID/DDs. Family caregivers supporting people with OTHER ID/DD were more likely to report negative outcomes than family caregivers supporting people with ID in the areas of feeling guilty about the balance of care given to the child with ID/DD versus other children, having negative marital outcomes, not getting a restful night's sleep, and not having a good balance between work, family and personal relationships. Family caregivers supporting people with severe ID/DD reported more negative social and family outcomes than family caregivers supporting mild ID/DD in every case. Family caregivers supporting people with moderate ID/DD reported more negative social and

family outcomes than family caregivers supporting people with mild ID/DD for 8 of the 13 outcomes.

CIVIC, SOCIAL AND COMMUNITY OUTCOMES OF CAREGIVING

More than half of family caregivers reported developing new values about life and what is important (62%), and being more aware of policy issues related to disability (52%; See Table 22). Fewer than half reported experiencing the other civic, social and community outcomes of care giving. Family caregivers supporting people with ID were more likely than family caregivers supporting people with ASD or OTHER ID/DD to report positive outcomes for eight of the 15 items. Family caregivers supporting people with moderate or severe ID/DD were more likely to report positive outcomes in five of the 15 listed areas. Family caregivers supporting children ages 0-13 were more likely to report positive civic, social or community outcomes than all other age groups for developing new life values (57%), and voting more regularly (24%). Family caregivers supporting children and young adults ages birth to 26 years reported more positive outcomes than family caregivers supporting people ages 27 years or older in five areas. Finally, family caregivers supporting people ages 14-26 were more likely to report that people in their community are always happy to see them and the person with ID/DD (20%).

CHALLENGES FOR FAMILY CAREGIVERS

Family caregivers were asked whether each of 33 challenges were not a problem, some problem or a major problem for them (See Table 23). More than half of all family caregivers reported *major* problems with having enough retirement savings (52%), finding non-institutional, community based care (51%), finding after school or summer care (50%), and finding affordable residential care (53%).

More than 80% of family caregivers having some or a major problem in having enough retirement savings (85%), finding trained and reliable home care providers (84%), finding non-institutional, community based care (82%), overall economic security (82%), balancing family responsibilities such as children, marriage and housework (82%), meeting needs for personal time and exercise (81%), finding afterschool or summer care (80%), and having enough money to pay for care (80%). More than half of all family caregivers reported having *some* or a *major* problem in 27 of the 33 areas listed.

Family caregivers supporting people with ASD or OTHER ID/DDs reported having more problems than family caregivers of people with ID in seven of the areas. Family caregivers supporting people with ASD reported experiencing more problems than family caregivers supporting people with ID in 23 of the 33 areas. Family caregivers supporting people with OTHER ID/DD were more likely than either of the other groups with ensuring the safety of the

person with ID/DD, modifying their home to meet care requirements, and getting information about the illness/disability of the person with ID/DD.

Family caregivers supporting people with severe ID/DD reported more problems than those with mild ID/DD finding non-institutional community based care, having enough money to pay for care, and doing end of life planning. They reported more problems than family caregivers supporting people with mild or moderate ID/DD in 20 of the 33 areas.

Family caregivers supporting people ages 40 years and older were less likely than family caregivers supporting those ages birth to 39 years to report problems with overall economic security. Family caregivers supporting people ages birth to 13 and 27 to 39 years were more likely than family caregivers supporting the other age groups to report challenges in having enough money to pay for care. Finally, family caregivers supporting people ages 27-39 were less likely than family caregivers supporting the other age groups to report problems communicating with professional resource providers.

DISCUSSION

SIMILARITIES AND DIFFERENCES BETWEEN FINDS RESULTS AND OTHER SIMILAR STUDIES

Several large surveys of supports and services for people with various disabilities have been conducted over the past two decades. In 1994 and 1995, the National Center for Health Statistics fielded a special supplement to the National Health Interview Survey (NHIS) focusing on people with disabilities identified from a national stratified random sample of more than 200,000 non-institutionalized people in the United States. The Research and Training Center on Community Living used NHIS-D results to describe the prevalence of ID/DD, to describe the characteristics and service needs of people with ID/DD, and to compare people with ID, DD, ID/DD and those with other types of disabilities (e.g., Larson, et al., 2001).

Other national surveys with information about the characteristics and needs of people with disabilities and/or the impact of disability on family include annual surveys of the National Residential Information Systems Project (focusing on living arrangements of adults and children with ID/DD; Lakin, Larson, Salmi and Webster, 2010), the 2003 National Survey of Children's Health (focusing on children with chronic emotional, developmental or behavioral problems; Blanchard, Gurka, and Blackman, 2003), the 2005-2006 National Survey of Children with Special Health Care Needs (comparing 2,088 children with ASD, to 9,534 children with other emotional, developmental or behavioral problems needs; e.g., Kogan, et al., 2008) and the National Core Indicators surveys (focusing on 6,778 adults with ID/DD from 26 states in 2008; e.g., Stancliffe, Lakin, Larson, Engler, Taub, & Fortune, 2010).

At least two large episodic surveys were fielded in 2010, The Arc's FINDS survey (described at length in this report), and the 2010 National FAST Family Support Survey of more than 2,400 parents and other family members from 54 states or U.S. territories that had completed parent advocacy training and had a child with disabilities between the ages of 11 and 39 (Larson, et al., 2011). Results from the FAST survey were reported separately for people with ID/DD, ASD, and other types of disabilities such as learning disabilities or emotional disturbances.

These other surveys all include data from or about people with ID/DD. However, some of the surveys included only people with ID/DD while others included people with other kinds of disabilities that may not be related to intellectual disability. This section compares findings from the FINDS survey to those of the other listed studies that reported on similar data elements.

DIFFERENCES IN AGE AND LIVING ARRANGEMENTS

Overall, 78% of family caregivers in The Arc FINDS survey lived with a person with ID/DD. This is very similar to the proportion of people with ID/DD of all ages reported to be living with family members in the NHIS-D survey. In that survey, an estimated 78% of people with ID/DD in the United States of all ages lived with family members, 8% lived alone or with unrelated people, 6% lived with a spouse, 6% lived in ID/DD congregate care settings, and 2% lived in state institutions or nursing homes (Larson, Doljanac & Lakin, 2005). The Residential Information Systems Project reported that 58% of people with intellectual or developmental disabilities receiving supports and services under the auspices of state developmental disabilities program agencies lived with family members or in host families in 2009 (Lakin, Larson, Salmi & Webster, 2010). By contrast, in the 2010 FAST Project Survey which focused on children and young adults, 93% of respondents lived with the person with disabilities (Larson et al., 2011).

The Arc FINDS survey included people ages 10 to 81 years (average 24.6 years). By contrast, the PACER FAST survey focused on people who were transition age (12 to 22 years; average 15.5 years).

DIFFERENCES IN DISABILITY TYPE

The population of interest for the FAST and FINDS surveys differed by both age and by disability type. In the FINDS survey, 62% had an intellectual disability, while the rest including 25% who had an autism spectrum disorder, and 13% who had an OTHER developmental disability (with Cerebral Palsy and mobility or physical impairments being the most common) were assumed to have developmental disabilities. The population for the FAST survey was much broader. In the FAST survey, 61% had an intellectual and/or developmental disability (including 36% who had an autism spectrum disorder), but 29% had a disability other than ID and/or DD (most commonly Attention Deficit Disorder, Emotional Disturbance or Specific Learning Disability).

The FAST survey focused on a younger population and included substantial numbers of children

who had a disability other than ID/DD, while the FINDS survey focused people of all ages who had ID/DD.

UNMET SUPPORT NEEDS

In The Arc FINDS survey, 62% of family caregivers reported that access to support services was decreasing, 32% reported that they were on a waiting list for residential, employment and other services and 9% reported losing a paid support person due to lack of funds. The most common unmet needs in the last year were assistance with leaving the house to do errands, shop or visit a doctor (48%), managing finances (46%), transportation (45%), caring for a household (41%), self-direction (38%), and job-coaching (30%). In all 35% of family caregivers reported unmet needs for special equipment, technology or assistive devices.

The large number of unmet needs reported in the FINDS survey has been reported in other studies as well. In 2009 the RISP project reported that residential services would need to grow by 28% to meet the needs of everyone waiting for some sort of residential support (Lakin, Larson, Salmi and Webster, 2010).

Parents in the 2010 PACER FAST survey reported significant unmet needs finding housing and support services (41%), preparing others to fulfill your role in the future (39%), financial assistance or income supports (39%), finding a support group for the son or daughter (38%), transportation (38%), finding and keeping a job (37%), preparing the child for healthy, loving adult relationships (36%), being prepared to work (34%), and finding and choosing vocational education, job training and employment programs (33%; Larson & Lakin, 2011). Parents with household incomes of less than \$20,000 per year reported more unmet needs than parents with household incomes of more than \$50,000 per year.

A 2001 study of 831 of mothers of adults with developmental disabilities from 33 states reported unmet needs in the areas of recreation and social activities (19%), occupational therapy (17%), vocational training (14%), psychological care (11%), dental care (10%), social work (9%), and transportation (12%). needs (Pruchno & McMullen, 2004).

In the 1994/1995 NHIS-D survey, many adults with ID/DD reported needing but being unsuccessful in attempts to hire people to provide needed supports (36%), needing help that has been discontinued (17%), or needing additional assistance with Instrumental Activities of Daily Living (cooking, cleaning, shopping, money management; 10%).

CAREGIVER/PARENT NEEDS AND OUTCOMES

Most family caregivers responding to the FINDS survey reported physical (88%) and financial (81%) strain. Due to the lack of or decrease in services, 71% of those family caregivers reported

care giving interfered with their work and 20% reported that someone in the family quit their job in order to provide care.

In the NHIS-D survey, family caregivers of children ages 6 to 17 years with functional limitations or ID/DD reported not taking a job (16%), changing work hours (16%), working fewer hours (15%), quitting work (11%), turning down a better job (9%), changing their sleeping patterns (9%), changing jobs (7%), or having severe financial problems (6%; Anderson, Larson, Lakin & Kwak, 2002). Overall, 31% of those families reported one or more of these challenges. Among families whose child had both intellectual and developmental disabilities 53% reported one or more of these challenges. Those parents reported that due to their child's health someone in the family had had not taken a job (36%), changed work hours (29%), worked fewer hours (26%), quit working (17%), changed sleep patterns (16%), turned down a better job (17%) or had severe financial problems (9%). It is not clear whether the differences between the FINDS results and the NHIS-D results is because of the 15 year gap between the surveys, because different age groups are compared, or because different survey methodology and sampling procedures were used.

In the 2003 National Survey of Children, caregivers supporting children with developmental challenges reported difficulties finding childcare, employment, and in demands related to parenthood. Nearly four times as many parents of a child with an emotional, developmental, or behavioral problem reported that they were not able to cope very well or not at all with the day-to-day demands of parenthood (5%) as compared to parents of children without developmental challenges (1%; Blanchard et al., 2006). Since the population group for the National Survey of Children included children with a variety of disabilities, not just those with ID/DD, it is again difficult to know whether these lower rates of family challenges are due surveying dissimilar populations, or whether the FINDS results indicate that this need has grown worse.

In the 2005-2006 National Survey of Children with Special Health Care Needs, financial difficulties related to the child's health care was reported by 39% of mothers of children with ASD, 30% of mothers of children with other EBD and 14% of parents of children with other health care needs (Kogan, et al., 2008). More than half of the mothers of children with ASD (57%) reported that a family member had to stop work or reduce hours due to the child's health care needs, compared with 36% of mothers of children with other EBD and 17% of mothers whose children had other health care needs.

In the FINDS survey, caregivers of people with ASD were more likely than other caregivers to report negative outcomes such as physical strain, financial strain, and emotional upset (See Table 20). Family caregivers supporting people with ASD were more likely to report fewer

services and supports and increased needs than did those supporting people with ID or an OTHER ID/DD.

Similarly, in the National Survey of Children with Special Health Care Needs mothers of children with ASD were more likely to report unmet service needs and greater negative outcomes related to their child's disability than mothers of children with other disabilities. Among mothers of children with ASD, 31% reported unmet needs for specific health care services and 19% reported unmet needs for family support services (Kogan, 2008). Whereas among mothers of children with emotional disorders, 25% reported unmet health care needs and 11% reported unmet family support needs.

Across these surveys, caregivers of people with disabilities report high levels of unmet support needs for the people with disabilities. Parents of children with ASD diagnoses consistently report more unmet needs and related negative outcomes than do parents of children with other types of disabilities, as do parents of people with more severe disabilities. These unmet needs put a serious strain on caregivers financially, physically and emotionally. The reports of high levels of stress and lack of supports have come from several different surveys spanning more than 15 years.

CONCLUSIONS AND STUDY LIMITATIONS

CONCLUSIONS

Numerous challenges and unmet needs were identified for people with ID/DD and their Family caregivers. Challenges remain in terms of

- Inclusive education- Only 29 to 39% of children depending on grade level are fully included in schools. 21% to 30% of children are educated in segregated schools. 27% of families reported that schools had cut back on services such as occupational, physical or speech therapy.
- Post-secondary education – While 58% of family caregivers reported it was very important for adults to continue their education after high school, 10% of adults with ID/DD did not complete high school, and 42% earned a certificate of completion rather than a diploma. Only 8% of adults had completed a college course.
- Residential supports – while 78% of families reported living with the person with ID/DD at the time of the survey, more than half reported the ideal residential setting for the person in adulthood was somewhere other than the family home and 61% of family caregivers worried that the person might have to live somewhere they did not want to.
- Daily supports – Family caregivers reported that 48% of people with ID/DD had an unmet need for help going outside the home to do errands, go shopping or visit the

doctor, 46% had unmet needs in the area of managing finances, 45% had unmet transportation needs, 41% had unmet needs for caring for their home, and 30% had unmet needs for job coaching or other job supports.

- Technology and assistive devices – 35% of family caregivers reported needing special equipment, technology or assistive devices they could not get.
- Waiting lists - 32% of family caregivers were waiting for government funded services such as personal support, respite or housing, with the wait averaging 5.3 years
- Family stress – Most family caregivers provided more than 80 hours of support each week (40%) or between 41 and 80 hours of support (18%) to the person with ID/DD. Overall, 18% of family caregivers paid for support from their own income, and 52% of those who received supports from someone other than a family member paid at least part of the cost for those services. Family caregivers reported being physically fatigued some or most of the time (88%), and more than 75% reported financial strain, emotional upset or stress in close personal relationships some or most of the time. 42% of family caregivers reported being very or extremely stressed. Fewer than half (47%) of family caregivers report they usually got a restful night's sleep.
- Quality and quantity of Supports – Between 20% and 40% of family caregivers (depending on grade level) were dissatisfied or very dissatisfied with the quality of education their family member received. Most family caregivers (between 44% and 57% depending on the type of service) were dissatisfied with the quality of government funded supports, and between 68% and 79% were dissatisfied with the amount of government funded supports. 62% of family caregivers reported that supports were decreasing in their communities.
- Employment and financial supports – Only 19% of adults with ID/DD had employment income and 25% had no source of personal income. While 63% of family caregivers preferred that the person in adulthood would work in a regular community job, only 7% of adults with ID/D worked in a regular community job.

In general, family caregivers of people with ASD reported more challenges than family caregivers of people with ID or OTHER ID/DDs.

Despite the progress that has been made in reducing institutionalization and increasing access to home and community based supports, many needs remain unmet. Family caregivers who are receiving supports report the quality and quantity of those supports are not adequate.

STUDY LIMITATIONS

People with ID/DD disabilities are a diverse group. Some people have an intellectual disability (an IQ of less than 70 to 75 existing concurrently with limitations in two or more skill areas manifested before age 18) but do not have a developmental disability (having significant

ongoing limitations in three major areas of life activity developed between birth and age 21). Others have a developmental disability caused by conditions such as cerebral palsy, spina bifida, epilepsy, autism, traumatic brain injury before age 22, or other related conditions, but have average or above average intelligence. A third group has both intellectual and developmental disabilities (Larson, Lakin, Anderson, Kwak, Lee & Anderson, 2001).

In this technical report, we tried to separate people with developmental disabilities only (those in the ASD and OTHER groups) from those with both intellectual and developmental disabilities (those in the ID group). However, these classifications were based solely on the diagnoses reported by family caregivers. The survey did not include questions about functional limitations in areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency, needed to determine if the person met the standard definition of developmental disabilities.

Possible problems with the classifications used in this report include:

- Some people classified as having ID may not have developmental disabilities (as defined by having three or more substantial functional limitations). This was often the case amongst people with ID/DD in the NHIS-D survey.
- Others in the ID group such as those with Fetal Alcohol Syndrome, Fragile X Syndrome and Prader-Willi Syndrome may have average or above average intellectual abilities. This may explain why 14% of the people in the ID group were not reported to have an intellectual disability.
- Learning disabilities require *average or above average* intellectual ability but specific difficulties in reading, math, social skills or other areas, yet 50% of the people with a diagnosis of ID which requires substantially *below average* intelligence, were reported to have learning disabilities.
- Some people in the ASD and OTHER groups may not have three or more functional limitations as required by the DD Act to be included as a developmental disability. People with mild cerebral palsy or Asperger's Syndrome, for example, may have some functional limitations but perhaps not the minimum three required by the DD Act.
- Other people in the ASD or OTHER group may have had intellectual disability but because their reported diagnosis was a related condition such as cerebral palsy they were included in the OTHER group instead. Table 3 shows that 43% of the people classified by diagnosis as having an OTHER type of disability were reported to have an intellectual disability as were 50% of those with a diagnosis of ASD.

Despite these possible limitations, we are confident that the vast majority of family caregivers who responded to the survey had family members with intellectual disabilities, developmental disabilities or both.

The results are representative of the people who heard about the survey and responded. It may not be representative of all family caregivers with a family member with ID/DD. Results may not be the same as if a scientific sample of family caregivers were surveyed.

This survey was only available to those with access to computers and the internet, and those that spoke English. It did not collect information from those that were unfamiliar with how to access or use an online survey, and it may not have engaged individuals that were not connected to disability systems of support or information, those that are older and do not use computers, or those from poor socioeconomic backgrounds. Equal representation across genders in the respondent pool was not achieved and as a result, perceptions do not represent perspectives from both genders equally. Ethnic and cultural minorities that do not speak English were not included. Equal representation from all states was not achieved.

While results cannot be generalizable to the entire population of families connected to ID/DD in the United States, the data may be considered to be a conservative indicator of some issues faced by the respondent population. The reason we say “conservative” is that people connected to the internet may have more discretionary income to pay for or access internet services and so our respondent pool may represent the more well-off families that are connected to ID/DD. The results here may not reflect the true depth of impact that the population is experiencing.

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Table 1 Finds Survey Respondents by State			
State	N	State	N
AK	4	NE	43
AL	27	NH	30
AR	14	NJ	262
AZ	25	NM	13
CA	127	NV	3
CO	125	NY	146
CT	59	OH	86
DC	27	OK	106
DE	6	OR	31
FL	184	PA	202
GA	73	PR	1
HI	27	PW	1
IA	71	RI	12
ID	2	SC	24
IL	268	SD	13
IN	69	TN	193
KS	34	TX	362
KY	19	UT	4
LA	50	VA	318
MA	308	VT	6
MD	232	WA	155
ME	15	WI	47
MH	1	WV	59
MI	211	WY	5
MN	97	Missing	665
MO	92	Total	5,287
MS	9		
MT	5		
NC	315		
ND	4		

Characteristic	%/N	Disability Type			F/X2	Sig.	Disability Level			F/X2	Sig.	PWD Age				F/X2	Sig.
		ID	ASD	Other			Mild	Moderate	Severe			0-13	14-26	27-39	40 +		
Gender (% Female) N=3329	89%	88%	91%	87%	6.70	*	88%	89%	88%	1.30		91%	88%	88%	89%	3.81	
Caregiver Age	N	2,126	830	425			641	1,733	936			793	1,031	479	389		
18 to 30	2%	2%	3%	3%	207.83	***	3%	2%	3%	10.18	*	2%	2%	3%	3%	28.05	***
31 to 50	44%	36%	64%	46%			47%	45%	41%			47%	39%	47%	52%		
51 to 100	58%	63%	34%	12%			50%	53%	57%			51%	59%	50%	45%		
Race/Ethnicity	3,220	2,035	781	404			608	1,661	884			764	973	459	363		
White/Caucasian (non-Hispanic)	90%	91%	89%	87%	11.46		89%	90%	90%	3.71		90%	90%	93%	85%	35.07	***
Black/African American	5%	4%	5%	7%			6%	4%	5%			5%	4%	3%	10%		
Latino/Hispanic	3%	3%	3%	3%			4%	3%	3%			3%	4%	2%	4%		
Asian American	1%	1%	2%	1%			1%	2%	2%			1%	1%	2%	0%		
Native American	1%	1%	1%	1%			0%	0%	0%			0%	1%	0%	1%		
Marital Status	3,300	2,080	807	413			623	1,688	918			780	1,004	471	367		
Single/never been married	4%	4%	5%	5%	12.81		5%	4%	5%	6.88		4%	5%	4%	5%	5.90	
Divorced/separated	15%	15%	16%	15%			14%	15%	17%			16%	15%	14%	14%		
Married	75%	75%	76%	72%			76%	75%	72%			75%	74%	75%	76%		
Widowed	4%	4%	2%	5%			4%	3%	4%			4%	4%	4%	3%		
Partnered/long-term relationship	2%	2%	2%	3%			2%	2%	2%			2%	2%	3%	2%		
Highest Education completed	3,312	2,090	812	410			622	1,699	920			782	1,009	469	370		
Some high school	1%	1%	1%	0%	14.53		1%	0%	1%	8.52		1%	1%	1%	1%	9.56	
High school degree	9%	8%	8%	12%			9%	9%	9%			8%	9%	9%	10%		
Some college	19%	19%	18%	21%			20%	18%	20%			19%	20%	18%	22%		
2 year college degree (Associate's)	11%	11%	11%	10%			10%	12%	10%			10%	12%	13%	12%		
4 year college degree (Bachelor's)	28%	27%	32%	27%			27%	29%	27%			29%	27%	30%	27%		
Post college or graduate degree	32%	33%	31%	30%			33%	32%	32%			33%	32%	29%	28%		
Family income before taxes	2,921	1,839	731	351			547	1,516	802			677	887	421	333		
I didn't have any income	1%	1%	2%	2%	26.30	*	0%	2%	2%	21.88		1%	1%	1%	1%	27.26	
Less than \$14,999	4%	3%	3%	5%			3%	3%	5%			3%	3%	5%	4%		
Between \$15,000 and \$21,999	5%	4%	6%	6%			5%	5%	5%			4%	6%	4%	7%		
Between \$22,000 and \$39,999	14%	14%	14%	18%			14%	14%	15%			17%	15%	12%	13%		
Between \$40,000 and \$59,999	19%	19%	19%	23%			20%	19%	18%			19%	20%	19%	20%		
Between \$60,000 and \$99,999	29%	31%	28%	24%			26%	32%	30%			27%	30%	31%	29%		
Between \$100,000 and \$200,000	23%	23%	24%	19%			25%	22%	22%			25%	21%	23%	23%		
Above \$200,000	4%	4%	4%	4%			6%	4%	4%			4%	4%	4%	3%		

Characteristic	%/ N	Disability Type			F/X2	Sig.	Disability Level			F/X2	Sig.	PWD Age				F/X2	Sig.
		ID	ASD	Other			Mild	Moderate	Severe			0-13	14-26	27-39	40 +		
Household size	3,318	2,094	813	411			625	1,703	919			779	1,012	474	373		
1	3%	4%	1%	5%	77.43 ***		3%	3%	3%	18.67		3%	4%	3%	2%	37.80	
2	20%	22%	13%	21%			19%	19%	22%			18%	22%	20%	17%		
3	31%	31%	29%	30%			30%	31%	31%			31%	32%	30%	26%		
4	28%	26%	36%	27%			29%	29%	27%			29%	26%	28%	31%		
5	13%	12%	15%	12%			12%	13%	12%			14%	11%	15%	14%		
6 or more	6%	6%	5%	5%			6%	4%	5%			5%	5%	4%	9%		
Mean Household Size	3.5	3.4	3.7	3.4	17.89 ***		3.5	3.5	3.4	0.70		3.5	3.4	3.4	3.7	7.81 ***	
Relationship to the Person with IDD	4,557	2,821	1,132	604			920	2,338	1,262			1,045	1,390	689	551		
Parent or step-parent	84%	82%	91%	81%	26.60 ***		84%	84%	82%	4.43		84%	84%	82%	81%	1.71	
Sibling	7%	9%	3%	6%	25.15 ***		6.4%	6.8%	8.6%	5.428		6%	7%	7%	8%	0.97	
Paid caregiver	6%	7%	3%	5%	12.19 ***		5%	6%	8%	5.61		6%	6%	8%	8%	1.98	
Non-related friend	5%	5%	3%	6%	3.23 *		5%	5%	5%	0.64		6%	5%	5%	5%	0.32	
Aunt/Uncle or other family member	3%	3%	3%	2%	2.47		3%	3%	4%	1.24		3%	3%	4%	3%	0.32	
Grandparent	2%	2%	2%	2%	0.08		2%	2%	2%	0.43		2%	2%	2%	3%	1.77	
Spouse	1%	0%	1%	2%	15.48 ***		1%	0%	0%	1.41		1%	1%	1%	1%	0.28	
Child	1%	0%	0%	2%	6.70 **		0%	0%	0%	0.73		0%	1%	0%	0%	0.68	
Partner/significant other	0%	0%	0%	0%	0.06		0%	0%	0%	0.35		0%	0%	1%	0%	0.12	
	3,841	2,322	1,013	505			758	1,937	1,012			899	1,189	574	446		
Caregiver is family member	95%	95%	97%	95%	6.78 *		95%	96%	96%	1.95		94%	95%	96%	96%	2.35	
Caregiver is not a family member	5%	5%	3%	5%			2%	5%	4%			6%	5%	5%	4%		
Do you live with the person you care for/support? (N=4535)	75%	71%	85%	75%	42.22 ***		78%	76%	71%	6.98 ***		77%	73%	75%	78%	7.18	

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type

a=Intellectual and Developmental Disabilities (IDD)
 b=Austim Spectrum Disorder (ASD)
 c=Other

Differences Age of Person

a=14-13 years
 b=14-26 years
 c=27-39 years
 d=40+ years

Greatest response

Differences: Level of Disability

a=Mild
 b=Moderate
 c=Severe

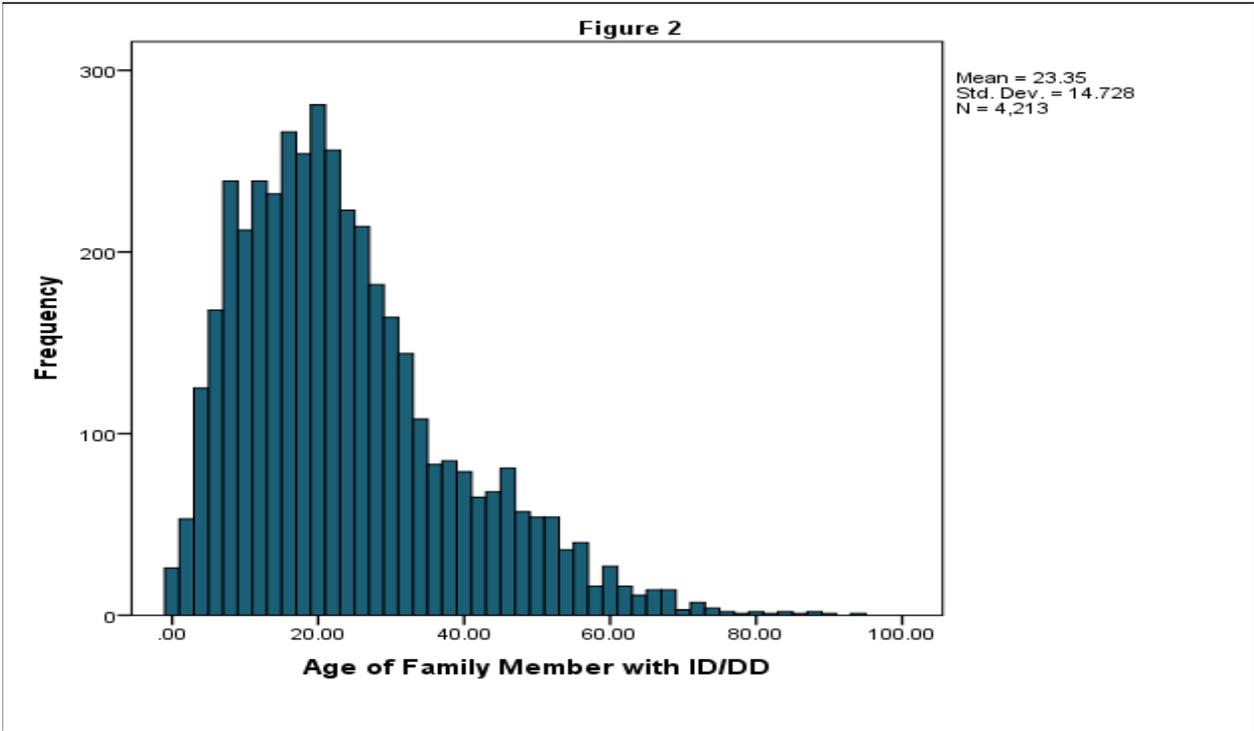
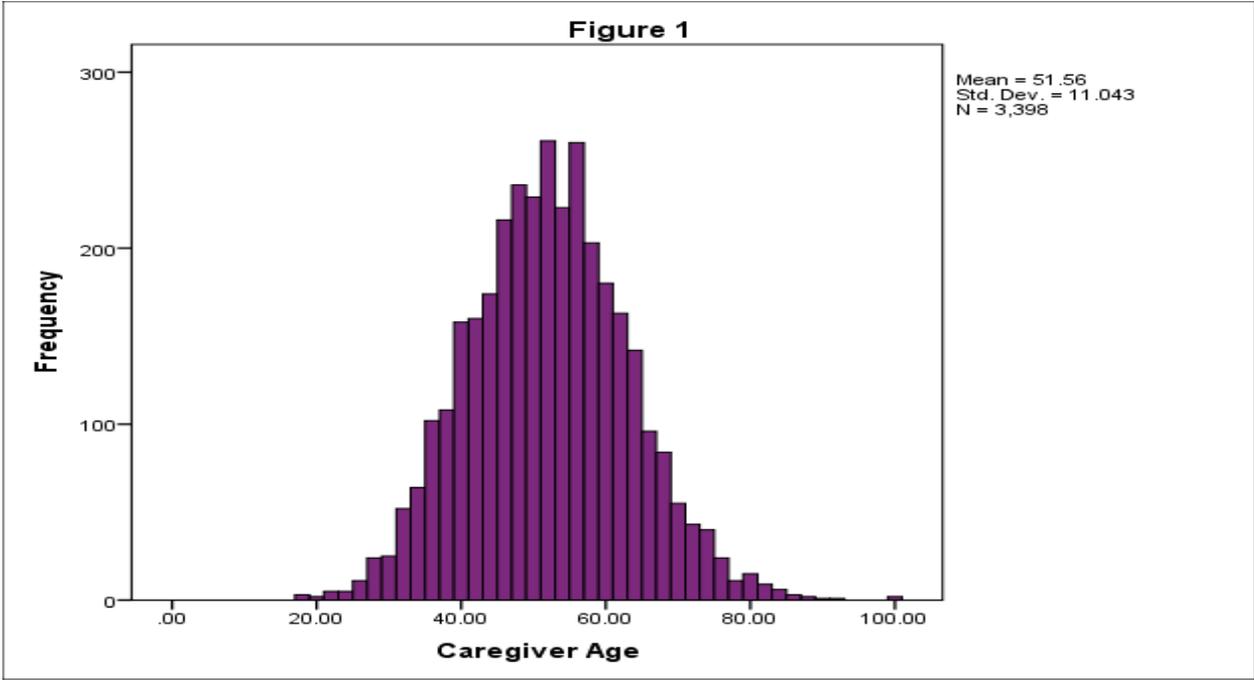


Table 3: Characteristics of the person with a disability

Characteristic	Total	Disability Type			F/X2 Sig.		Disability Level			F/X2 Sig.		Age Group				F/X2 Sig.	
		ID	ASD	Other	F/X2	Sig.	Mild	Moderate	Severe	F/X2	Sig.	0-13	14-26	27-39	40+	F/X2	Sig.
Age	N 4,661	2,293	895	494			734	1,831	987								
Birth to 13 years	28%	27%	30%	31%	49.98	***	27%	25%	28%	9.74							
14 to 26 years	38%	42%	30%	35%			36%	40%	39%								
27 to 39 years	19%	17%	25%	19%			20%	20%	18%								
40 years or older	15%	14%	15%	16%			17%	15%	15%								
Diagnosis (Mark all that apply)	N 4,216	2,616	1,094	506								989	1,334	659	510		
Intellectual disability	35%	57%	0%	0%	1,057.19	***	28%	33%	44%	28.62	***	33%	37%	31%	30%	4.64	**
Down syndrome	20%	32%	0%	0%	371.52	***	23%	24%	9%	61.63	***	20%	22%	14%	17%	7.69	***
Fetal alcohol syndrome	3%	6%	0%	0%	47.60	***	2%	4%	4%	3.10	*	1%	4%	2%	10%	29.31	***
Fragile X Syndrome	2%	3%	0%	0%	28.16	***	2%	2%	2%	1.80		2%	2%	4%	1%	4.60	**
Prader-Willi Syndrome	1%	1%	0%	0%	9.90	***	0%	1%	1%	0.36		1%	1%	1%	0%	0.93	
Autism	34%	21%	81%	0%	1,204.37	***	26%	34%	41%	24.12	***	34%	29%	37%	30%	5.78	***
Aspergers Syndrome	8%	3%	24%	0%	288.89	***	15%	9%	2%	50.78	***	8%	6%	11%	7%	4.45	**
Cerebral Palsy	16%	15%	3%	46%	286.27	***	3%	11%	31%	157.22	***	16%	16%	14%	14%	0.81	
Other (please specify)	29%	28%	27%	35%	5.19	**	29%	28%	30%	0.48		30%	35%	32%	31%	2.11	
No specific diagnosis	6%	4%	1%	28%	277.67	***	8%	6%	6%	2.49		7%	5%	7%	5%	1.82	
Traumatic Brain Injury	5%	4%	1%	18%	126.17	***	2%	4%	8%	24.86	***	5%	5%	4%	4%	0.43	
Spina Bifida	1%	1%	0%	2%	7.52	***	1%	1%	1%	1.32		1%	1%	1%	0%	0.66	
Disability (Mark all that apply)	N 4,533	2,812	1,119	602								1,045	1,405	698	546		
Intellectual disability	72%	86%	51%	43%	468.87	***	57%	73%	80%	142.28	***	70%	74%	63%	68%	9.09	***
Speech impairment	41%	42%	38%	41%	3.30	*	24%	39%	56%	223.56	***	44%	38%	40%	42%	0.49	
Learning disability	51%	50%	59%	45%	18.84	***	54%	53%	49%	6.96	*	51%	48%	52%	54%	1.94	
Mental, psychological, psychiatric, or emotional impairment	37%	35%	46%	28%	32.73	***	28%	39%	40%	42.51	***	35%	37%	40%	39%	2.02	
Mobility or physical impairment	27%	28%	8%	60%	312.74	***	11%	20%	52%	568.63	***	27%	28%	27%	26%	2.21	
Vision impairment	16%	18%	4%	26%	90.48	***	9%	13%	25%	129.73	***	13%	17%	15%	17%	1.28	
Traumatic brain injury	6%	5%	1%	17%	89.65	***	2%	5%	11%	80.71	***	5%	6%	4%	8%	1.32	
Hearing impairment	8%	10%	3%	10%	26.91	***	7%	9%	9%	2.46		8%	8%	10%	10%	2.52	
Other (please specify)	11%	11%	11%	11%	0.09		11%	11%	12%	1.65		12%	13%	13%	10%	2.66	*
Level of disability	N 4,445	2,744	1,113	588								939	1,384	689	540		
Mild	20%	18%	24%	21%	61.92	***						21%	19%	22%	23%	9.74	
Moderate	52%	53%	54%	42%								49%	53%	53%	50%		
Severe	28%	29%	22%	37%								30%	28%	25%	27%		

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Autism Spectrum Disorder (ASD)
c=Other

Differences: Age of Person
a=13-19 years
b=20-26 years
c=27-39 years
d=40+ years

Greatest response
Differences: Level of Disability
a=Mild
b=Moderate
c=Severe

Table 4: Educational attainments of people with disabilities

Education Completed	N	%	Disability Type			F/X2	Sig.	Diffs	Disability Level			F/X2	Sig.
			ID	ASD	Other				Mild	Moderate	Severe		
Highest Level of Education completed	881												
Some high school	84	10%											
High school certificate of completion	367	42%											
High school diploma	243	28%											
Post secondary certificate of completion for persons with disabilities	121	14%											
Some college	41	5%											
2 year college degree (Associate's)	10	1%											
4 year college degree (Bachelor's)	11	1%											
Post-college or graduate degree	4	1%											
Highest Level of Education Recoded													
Some high school	84	10%	8%	18%	10%	109.40	***		8%	9%	12%	28.12	***
High school certificate of completion	367	42%	49%	23%	26%				37%	42%	44%		
High school diploma	243	28%	24%	34%	32%				33%	30%	20%		
Post high school certificate of completion for persons with disabilities	121	14%	15%	11%	11%				8%	14%	17%		
Some college or more	66	8%	4%	15%	21%				14%	6%	6%		
At what age did you (or will you) begin planning for transition to adulthood? (Mean Age)	2,227	16.6	17.0	15.3	17.0	16.10	***	b<a,c	17.2	16.7	16.2	3.51	

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Austim Spectrum Disorder (ASD)
c=Other

Differences Age of Person
No age related differences were found | Highest education computed only if person was 18 years or older

Greatest response
Differences: Level of Disability
a=Mild
b=Moderate
c=Severe

Table 5: Use of public, private and home schooling by student's age

Grade Level	N	Disability Type												F/X2		Level of Disability												F/X2	
		Overall			ID			ASD			Other			Sig.	Mild			Moderate			Severe			Sig.					
		Public	Private	Home School	Public	Private	Home School	Public	Private	Home School	Public	Private	Home School		Public	Private	Home School	Public	Private	Home School	Public	Private	Home School						
Pre-K	2,893	71%	26%	2%	72%	26%	3%	69%	28%	3%	73%	24%	3%	2.26	66%	32%	3%	73%	25%	2%	73%	23%	4%	4.51	**				
Kindergarten	2,928	88%	12%	2%	87%	11%	2%	84%	13%	2%	87%	12%	1%	3.41	87%	12%	2%	86%	12%	2%	85%	13%	2%	0.80					
Primary School	3,131	86%	12%	3%	83%	14%	3%	87%	10%	2%	88%	10%	3%	11.93	86%	12%	2%	86%	11%	3%	84%	13%	3%	1.17					
Middle School	2,595	83%	14%	3%	84%	13%	3%	81%	16%	4%	84%	14%	2%	4.47	84%	13%	3%	85%	12%	3%	80%	17%	3%	1.34					
High School	2,556	83%	14%	3%	85%	12%	3%	76%	19%	5%	87%	11%	2%	27.49	84%	13%	3%	85%	12%	3%	81%	16%	3%	0.78					

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Level of Disability
a=Mild
b=Moderate
c=Severe

Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Autism Spectrum Disorder (ASD)
c=Other

Greatest response
There were no age related differences

Table 6: Caregiver satisfaction with quality of education for students with disabilities in various age groups

Setting	N	Satisfaction Level				Mean	Disability Type					Diffs	Level of Disability			Diffs		
		0 Very Dissatisfied	1 Dissatisfied	2 Satisfied	3 Very Satisfied		ID	ASD	Other	F/X2	Sig.		Mild	Moderate	Severe		F/X2	Sig.
Pre-K	3,164	8%	12%	43%	37%	2.1	2.1	2.0	2.1	3.63			2.2	2.1	2.0	9.64	***	c<a,b
Kindergarten	3,358	12%	22%	44%	23%	1.8	1.8	1.7	1.9	9.16	***	b<a,c	1.9	1.8	1.8	2.86	*	c<a
Primary School	2,673	14%	26%	42%	18%	1.7	1.7	1.6	1.7	1.40			1.7	1.7	1.6	3.97	*	c<a
Middle School	2,433	14%	26%	41%	19%	1.7	1.7	1.6	1.6	1.07			1.8	1.7	1.6	4.33	**	c<a
High School	691	16%	22%	41%	22%	1.7	1.7	1.6	1.9	3.02	*	a<c	1.8	1.7	1.6	3.04	*	c<a

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Greatest response

No Age differences noted

Differences: Disability Type
a=Intellectual and Developmental
b=Austim Spectrum Disorder (ASD)
c=Other

Differences: Level of Disability
a=Mild
b=Moderate
c=Severe

Table 7: School inclusion for students with disabilities

	Age Group				F/X2	Sig.	Diffs
	0-13	14-26	27-39	40+			
Levels of School							
Pre-K	1.6	1.6	1.7	1.8	4.15	**	a,b < d
Kindergarten	1.8	1.8	2.0	2.0	4.02	**	a < c,d
Primary School	1.8	1.7	1.9	1.9	7.74	***	b < c,d; a < d
Middle School	1.8	1.7	1.9	1.8	4.68	**	ns
High School	x	1.7	1.9	1.8	7.93	***	b < c

If at least one item

<p><u>Differences Age of Person</u> a=birth-13 years b=14-26 years c=27-39 years d=40+ years</p>
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Table 8: Caregiver views about post-secondary education

Post Secondary Education	%	Disability Type			F/X2	Sig.	Diffs	Level of Disability			F/X2	Sig.	Diffs	Age Group				F/X2	Sig.	Diffs
		ID	ASD	Other				Mild	Moderate	Severe				0-13	14-26	27-30	40+			
Importance of the person to continue their education after high school or go back to school as an adult to learn new things?	4,253	2,638	1,069	546				871	2,186	1,157				606	1,937	654	218			
Not Important	16%	20%	7%	14%	84.538 ***	a<c<b		6%	12%	30%	104.677 ***	c<b<a	15%	18%	14%	14%	1.18			
Somewhat Important	26%	30%	21%	22%				25%	29%	23%			26%	25%	26%	28%				
Very Important	58%	51%	72%	64%				68%	60%	47%			59%	58%	60%	58%				
Reasons why the person might take classes at a local community college, university, or trade or technical school? % Yes	3,690	2,197	1,003	480				142	355	168			537	1,652	565	199				
To learn a job-related skill	73%	73%	80%	62%	29.53 ***	b>a>c		78%	77%	59%	53.80 ***	c<a,b	72%	72%	75%	77%	1.72			
To learn about things they are interested in	72%	74%	69%	68%	5.43 ***	a>c		74%	74%	65%	12.46 ***	c<a,b	73%	74%	73%	67%	3.07 *	a>d		
To let them get experiences that will help them get a job	66%	65%	74%	56%	24.27 ***	b>a>c		73%	70%	50%	62.96	c<a,b	66%	66%	72%	66%	0.85			
To have a college experience	33%	29%	40%	38%	22.24 ***	b,c>a		43%	33%	24%	36.53 ***	c<b<a	35%	32%	35%	34%	0.99			
To obtain a technical degree or certification	27%	22%	38%	28%	47.67 ***	b>c>a		40%	27%	14%	67.13 ***	c<b<a	30%	25%	27%	26%	0.73			
To fulfill IEP plans	22%	23%	23%	17%	4.96 ***	a,b>c		16%	21%	31%	28.48 ***	a<b<c	19%	22%	24%	25%	4.36 **	a,b,c<d		
To obtain a certificate of completion	17%	16%	20%	15%	5.34 ***	a,c<b		19%	18%	12%	10.39 ***	c<a,b	19%	16%	17%	16%	1.14			
To learn travel training	16%	18%	16%	12%	6.26 ***	a,b>c		16%	18%	14%	3.75 *	a<b	16%	18%	15%	14%	0.84			
To earn a GED/high school diploma	14%	13%	16%	13%	2.21			15%	14%	11%	2.86 *	c<a	13%	13%	16%	13%	2.21			

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type

a=Intellectual and Developmental Disabilities (IDD)
 b=Austim Spectrum Disorder (ASD)
 c=Other

Greatest response

Differences: Level of Disability

a=Mild
 b=Moderate
 c=Severe

Differences Age of Person

a=birth-13 years
 b=14-26 years
 c=27-39 years
 d=40+ years

Table 9: Housing preferences (Caregiver survey)																				
Housing	%	Disability Type			F/X2	Sig.	Diffs	Level of Disability			F/X2	Sig.	Diffs	Age Group				F/X2	Sig.	Diffs
		ID	ASD	Other				Mild	Mod	Severe				0-13	14-26	27-30	40+			
Where does the person you care for live now?	4,343	2,126	865	447				664	1,742	962			542	1,803	614	187				
With family	78%	78%	78%	78%	17.08			76%	79%	78%	23.21		79%	76%	79%	81%	47.07			
In an apartment or house that s/he RENTs	6%	6%	7%	6%				7%	6%	6%			7%	7%	6%	7%				
Group home with 3 or fewer non-related pwd	5%	5%	5%	6%				5%	5%	6%			4%	6%	6%	4%				
Group home with 4 to 6 other non-related pwd	4%	4%	4%	5%				5%	4%	4%			2%	5%	4%	4%				
Other	2%	2%	2%	1%				2%	2%	2%			2%	2%	1%	1%				
In an apartment or house that s/he OWNs	1%	2%	.8%	1%				2%	1.4%	1%			1%	2%	1%	2%				
Residence that has 7 to 15 non-related pwd	1%	1%	1%	1%				2%	1%	1%			2%	1%	2%	1%				
Large congregate setting	2%	2%	2%	2%				3%	3%	3%			2%	3%	2%	1%				
Apartment or community that includes only pwd	0.7%	.8%	.7%	.2%				.6%	.7%	.7%			0%	1%	1%	0%				
Institution	0.6%	.7%	.5%	.4%				.5%	.5%	.8%			1%	1%	0%	0%				
Residence with more than 15 non-related pwd	0.3%	.2%	.3%	.2%				1.7%	1.3%	1.0%			0%	1%	0%	0%				
Military housing	0.2%	.1%	.3%	.2%				.2%	.3%	.0%			0%	0%	0%	0%				
Boarding home	0.2%	.2%	.2%	.2%				.0%	.1%	.5%			0%	0%	0%	0%				
Nursing home	0.2%	.3%	.1%	.2%				.1%	.1%	.0%			0%	0%	0%	0%				
Ideal living arrangement as an adult	3,937	2,463	967	507				781	1,990	1,079			978	1,282	635	445				
Where s/he lives right now	43%	44%	39%	44%	54.31 ***			40%	41%	51%	140.80 ***		42%	42%	45%	43%	34.08			
Apartment or house that s/he OWNs	20%	17%	26%	25%				27%	21%	13%			23%	21%	20%	19%				
Group home with 3 or fewer non-related pwd	16%	17%	15%	14%				3%	9%	5%			14%	16%	15%	18%				
In an apartment or house that s/he RENTs	8%	8%	8%	7%				12%	8%	6%			8%	8%	7%	8%				
Group home with 4 to 6 other non-related pwd	5%	5%	4%	4%				3%	5%	5%			5%	5%	5%	4%				
In someone else's home, like a family member	3%	3%	3%	3%				2%	3%	4%			3%	4%	3%	4%				
Large congregate setting	4%	5%	5%	4%				5%	4%	4%			5%	4%	5%	3%				
Nursing home	3%	3%	4%	3%				4%	3%	2%			3%	3%	3%	2%				
Residence that has 7 to 15 non-related pwd	1%	1%	0%	1%				0%	0%	1%			2%	0%	1%	0%				
Residence with more than 15 non-related pwd	0%	0%	0%	0%				0%	0%	1%			0%	0%	0%	0%				
Apartment or community that includes only pwd	0%	0%	0%	0%				0%	0%	0%			0%	0%	0%	0%				
Institution	0.2%	0.2%	0.0%	0.0%				0.1%	0.2%	0.2%			0%	0%	0%	0%				
Military housing	0.1%	0.1%	0.1%	0.0%				0.0%	0.1%	0.0%			0%	0%	0%	0%				
In a boarding home	0%	0%	0%	0%				0%	0%	0%			0%	0%	0%	0%				

Housing	%	Disability Type				F/X2	Sig.	Diffs	Level of Disability			F/X2	Sig.	Diffs	Age Group				F/X2	Sig.	Diffs
		ID	ASD	Other					Mild	Mod	Severe				0-13	14-26	27-30	40+			
Ideal roommates as an adult	4,557	2,821	1,132	604				900	2,318	1,250				1,186	1,602	807	618				
Roommates that s/he chooses	36%	37%	34%	35%	2.53			39%	38%	28%	19.64 ***	c<a,b	37%	34%	31%	28%	5.57 ***				
One or both parents, while living	28%	28%	29%	27%	0.42			23%	26%	35%	24.81 ***	a,b<c	27%	25%	26%	22%	1.61				
Live alone	10%	8%	14%	13%	19.55 ***	b,c > a		15%	10%	8%	16.56 ***	b,c<a	10%	9%	10%	9%	0.44				
Siblings or other family members	10%	10%	10%	10%	0.06			8%	10%	10%	1.78		9%	9%	9%	9%	0.14				
Other (Please specify)	10%	10%	9%	9%	0.56			10%	9%	11%	1.74		8%	9%	10%	8%	0.57				
Roommates that s/he is assigned	7%	8%	7%	6%	0.79			6%	8%	8%	0.95		6%	6%	8%	6%	1.25				
Do you: (check all that apply)	4,171	2,598	1,042	531				820	2,118	1,147				964	1,271	621	491				
Worry that the person you support might have to go live somewhere that they don't want to go	61%	62%	63%	53%	7.83 ***	a,b>c		47%	64%	66%	43.12 ***	a<b,c	62%	63%	60%	60%	0.72				
Have a plan of where the person you care for/support will live once you get older	38%	43%	26%	35%	46.51 ***	a>c>b		39%	36%	40%	2.72		38%	39%	35%	35%	1.64				
Haven't thought about what future housing options might be for the person I support	17%	12%	26%	24%	63.43 ***	b,c>a		27%	16%	12%	38.29 ***	c<b<a	18%	15%	19%	21%	3.88				

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type

a=Intellectual and Developmental Disabilities (IDD)

b=Autism Spectrum Disorder (ASD)

c=Other

Families whose member was 13 years old or younger were more likely than families whose member was older to report that the ideal roommate would be a someone the person chooses (37%, 34%, 31%, 28%)

Greatest response

Differences: Level of Disability

a=Mild

b=Moderate

c=Severe

Differences Age of Person

a=13-19 years

b=20-26 years

c=27-33 years

d=34+ years

Table 10: Disability related supports needed but not available

Person needed help during the last year but was unable to get that help	N	Total	Disability Type			F/X2	Sig.	Diffs	Level of Disability			F/X2	Sig.	Diffs
			ID	ASD	Other				Mild	Mod	Severe			
Going outside the home to do errands, go shopping or visit a doctor	2,722	48%	49%	40%	51%	8.39	***	b<a,c	56%	47%	44%	9.33	***	b,c<a
Managing finances, such as keeping track of your money and paying bills	2,106	46%	49%	32%	57%	25.12	***	b<a<c	46%	42%	57%	15.91	***	a,b<c
Transportation	2,673	45%	46%	39%	50%	7.20	***	b<a,c	51%	42%	48%	7.59	***	b<a,c
Taking care of a household	2,215	41%	43%	31%	47%	13.66	***	b<a,c	50%	40%	39%	7.55	***	b,c<a
Self direction	2,942	38%	40%	30%	45%	16.35	***	b<a,c	46%	36%	37%	9.73	***	b,c<a
Job coaching or on-the-job support	1,911	30%	34%	16%	29%	26.01	***	b<a,c	41%	28%	28%	12.69	***	b,c<a
Social activities	3,377	30%	34%	18%	35%	39.69	***	b<a,c	35%	29%	31%	4.13	*	b<a
Getting a job	1,827	28%	32%	14%	27%	25.12	***	b<a,c	38%	25%	26%	11.40	***	b,c<a

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Greatest response

No age differences noted

Differences: Level of Disability

Differences: Disability Type

a=Intellectual and Developmental Disabilities (IDD)

b=Austim Spectrum Disorder (ASD)

c=Other

a=Mild

b=Moderate

c=Severe

Table 11a: Paid and unpaid supports provided to the person with a disability by the respondent or another family member

Care Characteristics	N	% Yes	Disability Type			Comparisons			Disability Level			Comparisons			Age Group				Comparisons		
			ID	ASD	Other	F/X2	Sig.	Diff	Mild	Mod.	Severe	F/X2	Sig.	Diff	0-13	14-26	27-39	40+	F/X2	Sig.	Diff
Type of care or support you provide	3,913		1,907	771	411				575	1,560	863				926	1,085	511	375			
Providing emotional reassurance		86%	87%	85%	84%	1.30			84%	87%	87%	1.70			82%	88%	88%	86%	5.31	***	a<c,d
Transportation		84%	83%	84%	84%	0.19			82%	85%	83%	1.93			75%	87%	86%	88%	20.34	***	a<b,c,d
Cooking, laundry, house cleaning		80%	81%	80%	80%	0.08			79%	82%	81%	0.98			72%	83%	83%	82%	16.28	***	a<b,c,d
Managing financial affairs		78%	78%	77%	82%	2.04			79%	79%	78%	0.75			72%	82%	81%	78%	9.69	***	a<b,c,d
Social arrangements		77%	77%	78%	75%	0.72			74%	78%	78%	2.12			73%	79%	77%	77%	3.50		
Arranging and monitoring outside help or services		76%	76%	76%	75%	0.08			78%	76%	75%	0.55			72%	77%	79%	79%	4.64	**	a<c,d
Home maintenance		74%	75%	71%	74%	1.46			73%	75%	76%	4.52	**	a<b	68%	77%	77%	76%	8.47	***	a<b,c,d
Providing direct financial support		72%	73%	73%	71%	0.24			67%	72%	72%	2.45			69%	74%	74%	74%	3.02		
Support at recreational activities		71%	71%	73%	68%	1.73			70%	75%	72%	2.43			64%	74%	74%	71%	9.05	***	a<b,c,d
Administering medications		69%	68%	69%	69%	0.09			67%	70%	68%	0.86			63%	69%	70%	72%	4.85	**	a<b,c,d
Personal care (such as bathing, feeding, dressing, etc.)		61%	60%	62%	64%	0.93			59%	61%	62%	0.87			57%	60%	65%	63%	3.21	*	a<d
Coordinating community services – or services with a local religious institution		58%	58%	58%	56%	0.27			57%	57%	58%	0.04			56%	59%	55%	59%	0.91		
Other (please specify)		11%	11%	13%	11%	1.22			10%	8%	8%	1.40			43%	0%	0%	0%	501.13	***	b,c,d<a
Providing sign language interpretation		10%	10%	12%	11%	1.84			9%	10%	12%	1.32			11%	10%	9%	10%	0.99		
Hours PER WEEK you spend providing care/support	3,875		2,401	962	496				748	1,974	1,060				892	1,188	561	451			
15 hours or less per week		21%	23%	15%	22%	36.79	***		31%	19%	18%	124.83	***		20%	20%	18%	43%	10.06		
15-40 hours per week		21%	22%	21%	19%				23%	23%	15%				23%	21%	18%	38%			
41-80 hours per week		18%	18%	20%	18%				13%	20%	17%				23%	19%	17%	42%			
More than 80 hours per week		40%	38%	45%	41%				33%	38%	50%				18%	21%	20%	41%			
Family member(s) paid for support provided	3,847	18%	18%	15%	19%	5.58			15%	22%	23%	23.58	***	a<b<c	15%	17%	19%	20%	5.54		
Source of funds used to pay family members			428	142	94				86	309	250				134	198	104	87			
Medicaid HCBS Waiver		52%	54%	51%	62%	4.76	**	b<c	49%	49%	59%	3.21	*		49%	53%	62%	48%	2.10		
Personal income of parent, family member or other caregiver		29%	27%	40%	21%	6.21	**	a,c < b	40%	29%	29%	3.21	*	c<a	32%	29%	24%	30%	0.63		
Other (please specify)		24%	26%	21%	20%	1.03			17%	27%	22%	1.99			23%	24%	17%	33%	2.28		
Personal income of person with disabilities		16%	18%	14%	11%	1.95			20%	16%	16%	0.42			16%	15%	18%	16%	0.16		
Personal savings of parent, family member or other caregiver		7%	7%	8%	4%	0.79			7%	6%	8%	0.51			10%	5%	4%	9%	1.68		
Personal savings of person with disabilities		2%	1%	2%	2%	0.24			2%	1%	2%	0.95			2%	3%	0%	1%	0.98		
Special Needs Trust		2%	3%	1%	2%	0.45			5%	1%	4%	2.95			4%	2%	2%	1%	1.05		
Private Insurance		2%	2%	1%	3%	0.61			1%	2%	1%	0.55			4%	2%	0%	1%	2.40		
Personal or family sources combined		40%	38%	51%	29%	6.22	**	a,c<b	56%	40%	34%	6.21	**	b,c<a	45%	41%	37%	34%	0.99		

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type

a=Intellectual and Developmental Disabilities (IDD)

b=Austim Spectrum Disorder (ASD)

c=Other

Greatest response

Differences: Level of Disability

a=Mild

b=Moderate

c=Severe

Differences Age of Person

a=birth-13 years

b=14-26 years

c=27-39 years

d=40+ years

Table 11b: Supports provided to the person with a disability by someone not in the family

Care Characteristics	N	% Yes	Disability Type			Comparisons			Disability Level			Comparisons			Age Group				Comparisons		
			ID	ASD	Other	F/X2	Sig.	Diff.	Mild	Mod.	Severe	F/X2	Sig.	Diff.	0-13	14-26	27-39	40+	F/X2	Sig.	Diff.
How much is spent in a typical month on care provided by a non-family member?	3,238		2,018	795	414				610	1,632	912				761	973	5	374			
None		38%	37%	41%	38%	42.91	***		54%	40%	25%	234.31	***		41%	37%	41%	15%	17.84		
Less than \$100 per month		9%	9%	10%	6%				10%	9%	7%				7%	8%	9%	12%			
\$100 - \$249 per month		10%	9%	10%	12%				9%	10%	10%				9%	10%	9%	9%			
\$250-\$499 per month		11%	11%	14%	9%				10%	12%	11%				11%	12%	11%	10%			
\$500-\$999 per month		12%	11%	12%	14%				9%	12%	13%				10%	12%	11%	12%			
\$1000-\$1499 per month		7%	8%	5%	8%				3%	7%	9%				6%	7%	6%	7%			
\$1500+ per month		14%	15%	9%	15%				5%	11%	25%				15%	16%	13%	10%			
Source of funds to pay for supports from a non-family member	1,972		1,255	462	255				278	965	677				445	609	274	226			
Personal income of parent, family member or other caregiver		52%	47%	67%	47%	28.08	***	a,c <b	58%	53%	46%	7.39	**	c<a,b	59%	48%	49%	52%	4.47	**	b<a
Medicaid HCBS Waiver		50%	54%	36%	55%	24.24	***	b<a,c	35%	47%	58%	23.57	***	a<b<c	43%	55%	58%	48%	7.50	***	a<b,c,d d < c
Personal income of person with disabilities		21%	24%	16%	17%	8.32	***	b,c<a	19%	22%	20%	0.96			16%	22%	21%	19%	2.08		
Other		19%	15%	20%	19%	2.32			12%	19%	21%	4.84	**	a<b,c	20%	17%	16%	18%	0.89		
Personal savings of parent, family member or other caregiver		12%	10%	17%	10%	8.93	***	a,c<b	11%	13%	11%	0.72			15%	10%	13%	9%	2.60		
Private Insurance		8%	7%	8%	8%	0.47			8%	7%	9%	0.76			8%	8%	10%	6%	0.96		
Personal savings of person with disabilities		3%	2%	3%	5%	4.46	*	a<c	3%	3%	2%	0.30			2%	3%	2%	1%	1.02		
Special Needs Trust		3%	4%	1%	4%	4.51	*	b<a,c	2%	4%	3%	0.77			4%	4%	3%	2%	1.02		
Personal or family sources combined		63%	60%	74%	58%	16.64	***	a,c<b	71%	65%	57%	9.33	***	c<a,b	65%	61%	64%	60%	1.08		

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type

a=Intellectual and Developmental Disabilities (IDD)

b=Austim Spectrum Disorder (ASD)

c=Other

Greatest response

Differences: Level of Disability

a=Mild

b=Moderate

c=Severe

Differences Age of Person

a=0-13 years

b=14-26 years

c=27-39 years

d=40+ years

Table 12: Caregiver satisfaction with services and supports received

Satisfaction with	N	% satisfied	Disability Type				Diifs	Disability Level			Comparisons			
			ID	ASD	Other	F/X2		Sig.	Mild	Mod.	Severe	F/X2	Sig.	Diifs
Government funded services and														
Quality:														
Personal Support	1,687	56%	58%	44%	64%	13.10	***	b<a,c	54%	53%	61%	5.01	**	a,b<c
Housing	1,060	50%	54%	35%	50%	11.31	***	b<a,c	52%	47%	57%	3.64	*	
Transportation	1,290	56%	59%	45%	55%	6.66	**	b<a,c	57%	55%	59%	0.78		
Employment	556	43%	45%	31%	46%	3.60	*		50%	39%	47%	2.17		
Therapy Services	1,271	51%	52%	45%	54%	2.65			52%	49%	53%	0.69		
Respite Care	1,086	55%	57%	50%	55%	1.80			55%	54%	57%	0.45		
Amount:														
Personal Support	2,089	27%	29%	20%	27%	8.38	***	b<a,c	27%	25%	29%	1.38		
Housing	1,248	23%	26%	17%	18%	5.54	**	b<a	21%	22%	27%	1.90		
Transportation	1,596	32%	33%	28%	33%	1.77			32%	32%	32%	0.10		
Employment	717	23%	26%	14%	20%	5.29	**	b<a	25%	23%	22%	0.20		
Therapy Services	1,886	21%	22%	17%	24%	4.03	*	b<c	24%	21%	20%	1.35		
Respite Care	1,730	22%	22%	21%	23%	0.10			22%	22%	22%	0.02		
Private-pay services and support:														
Quality:														
Personal Support	813	70%	70%	67%	73%	0.56			63%	70%	73%	1.94		
Housing	476	60%	60%	57%	67%	0.84			49%	61%	65%	5.44	**	a<c
Transportation	581	64%	64%	55%	80%	5.23	*	a,b <c	61%	62%	67%	2.51		
Employment	182	47%	47%	26%	61%	3.78	*	b<c	41%	42%	51%	0.58		
Therapy Services	780	68%	66%	69%	74%	1.28			72%	66%	68%	0.99		
Respite Care	582	61%	63%	63%	74%	1.45			58%	64%	65%	0.81		
Amount:														
Personal Support	963	30%	32%	26%	28%	1.84			30%	30%	29%	0.11		
Housing	575	28%	31%	18%	30%	4.33	*		25%	27%	32%	0.77		
Transportation	695	28%	30%	22%	33%	2.37			30%	28%	29%	0.13		
Employment	276	18%	18%	15%	23%	0.47	*		23%	15%	20%	1.22		
Therapy Services	1,032	30%	31%	26%	32%	1.50			34%	28%	30%	1.20		
Respite Care	852	20%	20%	18%	27%	1.39			19%	20%	20%	0.05		

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Austim Spectrum Disorder (ASD)
c=Other

Differences: Level of Disability	Least satisfied
a=Mild	No differences noted for age group
b=Moderate	
c=Severe	

Table 13: Waiting lists and sources of income for the person with a disability

	N	% Yes	Disability Type			F/X2	Sig.	Diffs	Level of Disability			F/X2	Sig.	Diffs
			ID	ASD	Other				Mild	Moderate	Severe			
Are you now waiting for government funded services:	3,829	32%	32%	37%	26%	16.20	***	a,b>c	27%	34%	32%	7.10	***	a<b,c
How long has the person been waiting? (years)	1,123	5.3	5.6	4.6	5.1	6.05	**	a>b	5.2	5.2	5.4	0.28		
What services are they waiting for? (Mark all that apply)	4,557		2,821	1,132	604				900	2,318	1,250			
Personal support assistance		14%	14%	15%	10%	5.44	**	a,b>c	11%	15%	13%	5.72	**	a<b
Respite care		11%	10%	13%	8%	7.97	***	b>a,c	8%	11%	12%	5.48	**	a<b,c
Community-based housing		10%	12%	7%	7%	16.54	***	a>b,c	8%	11%	9%	5.02	**	a<b
Therapy services		9%	7%	14%	8%	20.79	***	b>a,c	7%	10%	9%	4.20	*	a<b,c
Employment (Job coaching or on-the-job supports)		7%	8%	6%	4%	4.20	*	a>c	6%	8%	4%	12.85	***	c<a,b
Transportation		5%	6%	4%	3%	7.64	***	a>b,c	4%	6%	4%	4.24	*	a<b
Other (please specify)		9%	8%	10%	8%	2.21			6%	9%	10%	5.51	**	a<b,c
We don't know how to get on a waiting list for services		7%	6%	9%	8%	6.95	***	b>a	7%	8%	6%	2.16		
Sources of personal income for adults with a disability: (Mark all that apply)	2,168		1,338	539	291									
Supplemental Security Income (SSI)		33%	36%	24%	32%	13.28	***	b<a,c	24%	33%	38%	12.45	***	a<b,c
Family		30%	31%	28%	25%	2.33			31%	32%	25%	4.34	*	c<a,b
Social Security Disability or Retirement Insurance (OASDI)		21%	25%	11%	22%	20.96	***	b<a,c	17%	22%	22%	2.56		
Employment income (wages and earnings from paid employment for those 18 years or older)		19%	22%	12%	16%	12.25	***	b,c<a	26%	21%	10%	24.36	***	c<b<a
Private disability insurance		1%	1%	0%	2%	3.90	*	a,b<c	0%	1%	1%	0.42		
Pension Program		1%	0%	1%	2%	8.98	***	a,b<c	1%	0%	1%	4.31	*	b<a
Workers' Compensation		0%	0%	0%	0%	0.62			0%	0%	0%	0.71		
The person I care for has no personal income		25%	21%	38%	23%	31.03	***	b<a,c	31%	25%	22%	5.21	**	b,c<a
Other (please describe)		7%	7%	6%	5%	1.23			6%	6%	8%	1.85		
Don't Know		1%	1%	1%	1%	0.54			0%	1%	2%	5.94	**	a,b<c

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Austim Spectrum Disorder (ASD)
c=Other

No age related differences noted

Greatest response

Differences: Level of Disability
a=Mild
b=Moderate
c=Severe

Important Services and Supports	%	Disability Type			Level of Disability			Age Group				F/X2	Sig.	Diffs							
		ID	ASD	Other	Mild	Moderate	Severe	0-13	14-26	27-39	40+										
		F/X2	Sig.	Diffs	F/X2	Sig.	Diffs	F/X2	Sig.	Diffs											
N	3,342	2,102	826	414				624	1,712	931					779	1,028	472	383			
Advocacy services to help get our local system to provide more supports	74%	74%	78%	68%	7.50 ***	a,b>c		70%	74%	77%	4.26 *	a<c			76%	75%	73%	72%	1.13		
Recreation services	62%	62%	66%	58%	3.94 *	b>c		55%	65%	62%	10.00 ***	a<c,b			64%	61%	62%	61%	0.63		
Information about what services my state offers	62%	61%	65%	60%	2.30			58%	63%	62%	2.72				63%	60%	60%	63%	0.72		
Information about local services and programs	59%	57%	65%	54%	8.86 ***	b>a,c		57%	60%	58%	0.96				58%	58%	58%	61%	0.43		
Information about family support services	54%	51%	62%	51%	13.85 ***	b>a,c		45%	55%	59%	15.07 ***	a<b,c			54%	53%	54%	54%	0.07		
Advocacy services to help me understand our family and the person's rights	53%	51%	62%	49%	15.12 ***	b>a,c		52%	53%	56%	1.91				55%	52%	54%	54%	0.62		
Physical activities and sports programs	53%	53%	55%	50%	2.01			49%	57%	50%	9.83 ***	a,c<b			53%	54%	54%	50%	0.68		
Information about new technologies that could make life easier	52%	50%	52%	61%	8.16 ***	c>a,b		39%	50%	63%	47.30 ***	a<b<c			54%	52%	49%	52%	1.21		
Transportation services	52%	54%	46%	50%	8.50 ***	a>b		45%	54%	52%	7.88 ***	a<b,c			49%	54%	51%	49%	1.88		
Special Needs Trusts/ Financial Planning	51%	49%	58%	49%	9.12 ***	b>a,c		50%	47%	36%	20.23 ***	c<a,b			51%	51%	51%	50%	0.06		
Inclusive programs in the community	50%	50%	52%	45%	2.83	b>c		46%	53%	47%	6.67 **	a,c<b			51%	51%	49%	45%	1.50		
Legal services to challenge wrongful treatment or lack of access to services	50%	49%	54%	46%	4.53 *	a>c		43%	49%	55%	10.99 ***				52%	50%	51%	47%	1.16		
Respite services	50%	48%	54%	47%	3.88 *	b>c		35%	49%	60%	51.02 ***	a<b<c			49%	49%	48%	49%	0.04		
Help navigating services to help understand the different systems, paperwork, and deadlines	49%	49%	53%	44%	4.33 *	b>c		42%	50%	52%	7.20 **	a<b,c			50%	50%	49%	47%	0.27		
Information about benefits counseling	49%	48%	54%	43%	7.91 ***	b>a>c		46%	51%	48%	2.57				50%	48%	50%	48%	0.38		
Therapeutic services (Occupational, Physical, Speech therapies)	46%	42%	54%	52%	22.04 ***	b,c>a		37%	44%	57%	34.85 ***	a<b<c			47%	45%	49%	44%	1.00		
Home and community-based residential services	45%	48%	41%	41%	6.41 **	a>b,c		30%	45%	55%	49.54 ***	a<b<c			45%	46%	39%	46%	2.40		
Self-advocacy programs	44%	42%	50%	42%	6.63 **	b>a,c		49%	47%	35%	20.06 ***	c<a,b			46%	43%	44%	44%	0.46		
Job coaching services	44%	44%	48%	37%	6.65 **	a,b>c		46%	51%	28%	65.66 ***	c<a<b			43%	43%	45%	43%	0.22		
Long term care supports and services	43%	45%	41%	39%	4.44 *	a>c		27%	42%	57%	71.67 ***	a<b<c			41%	46%	40%	44%	2.23		
Information about what's going on in Washington, DC with policy issues	42%	43%	42%	41%	0.35			36%	42%	47%	8.23 ***	a<b<c			45%	43%	43%	40%	0.88		
Independent living services	42%	42%	45%	38%	2.58	b>c		47%	47%	29%	46.08 ***	c<a,b			41%	44%	40%	42%	0.88		
Information on inclusive childcare/aftercare/summer care	36%	33%	47%	30%	31.14 ***	b>a,c		32%	35%	40%	5.24 **	a<c			39%	33%	36%	38%	2.41		
Personal attendant services	36%	36%	34%	37%	1.00			21%	32%	52%	92.94 ***	a<b<c			35%	36%	33%	34%	0.71		
Volunteer programs	33%	34%	30%	32%	2.09			32%	35%	28%	7.57 **	c<b			34%	36%	28%	27%	5.50 ***	d<a,b; c<b	
Internship programs at local businesses	30%	29%	34%	25%	6.02 **	b>c		36%	34%	18%	45.71 ***	c<a,b			31%	29%	29%	30%	0.26		
Programs for siblings	29%	26%	37%	29%	17.67 ***	b>a,c		27%	30%	29%	1.07				30%	27%	30%	31%	1.21		
Accessibility supports (home)	29%	28%	23%	44%	29.08 ***	c>a,b		17%	23%	49%	134.36 ***	a<b<c			29%	30%	27%	30%	0.43		
Accessibility supports (work settings)	24%	24%	24%	29%	2.91	c>a,b		20%	25%	25%	3.18 *	a<b,c			23%	26%	22%	27%	1.27		
I don't know	0%	0%	0%	0%	1.42			0%	0%	0%	0.35				0%	0%	0%	0%	1.99		

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Greatest response

Differences: Disability Type

a=Intellectual and Developmental Disabilities (IDD)
b=Autism Spectrum Disorder (ASD)
c=Other

Differences: Level of Disability

a=Mild
b=Moderate
c=Severe

Differences: Age of PWD

a=13-19 years
b=20-26 years
c=27-39 years
d=40+ years

Table 14b: Sources of health insurance for the person with a disability

Sources of health insurance for the person (Check all that apply)	%/N	Disability Type			F/X2	Sig.	Diffs	Level of Disability			F/X2	Sig.	Diffs	Age Group				F/X2	Sig.	Diffs
		ID	ASD	Other				Mild	Moderate	Severe				0-13	14-26	27-39	40+			
	N	3,353	2,116	817	420			2,116	817	420			789	1,037	474	383				
Health insurance through individual with disabilities' employer	2%	2%	0%	2%	3.90 *	b<a,c	3%	1%	1%	10.99 ***	b,c<a	2%	2%	1%	1%	1.19				
No health insurance	1%	1%	2%	2%	1.65		2%	1%	1%	2.37 *	c<a	2%	2%	1%	1%	0.93				
Public Health Insurance Programs																				
Medicaid, Medical Assistance, or a state program that pays health care for people with low incomes	60%	66%	45%	63%	58.98 ***	b<a,c	44%	59%	73%	67.20 ***	a<b<c	58%	64%	61%	56%	3.85 **	b > d			
Medicare (the government plan that pays healthcare bills for people ages 65 and older and for some young people with disabilities)	24%	29%	11%	27%	51.47 ***	b<a,c	22%	25%	25%	1.05		22%	26%	24%	22%	1.10				
Either or both of the public sources	69%	76%	51%	74%	90.20 ***	b<a,c	54%	68%	82%	70.91 ***	a<b<c	66%	74%	70%	65%	5.71 **	a,d<b			
Family funded sources																				
Health insurance through parents, or other family members, employer	59%	55%	72%	53%	42.56 ***	b>a,c	64%	59%	54%	8.01 ***	b,c<a	60%	55%	61%	62%	3.45 *				
Individual health insurance policy bought directly by me or another member of my family for person with disabilities	3%	2%	3%	3%	0.67		2%	3%	3%	0.49		3%	3%	2%	2%	0.38				
Either or both of the family sources	62%	57%	75%	55%	44.55 ***	a,c<b	66%	61%	56%	7.72 ***	c<a,b	63%	57%	63%	64%	2.78 *	ns			
Has both publicly funded and family funded insurance	32%	34%	27%	32%	5.68 **	b<a	24%	31%	39%	19.61 ***	a<b<c	31%	33%	34%	31%	0.70				

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type

a=Intellectual and Developmental Disabilities (IDD)
 b=Austim Spectrum Disorder (ASD)
 c=Other

Greatest response

Differences: Level of Disability

a=Mild
 b=Moderate
 c=Severe

Differences: Age of PWD

a=birth-13 years
 b=14-26 years
 c=27-39 years
 d=40+ years

Table 15 Supports Used by Person with a Disability or the Caregiver

Types of Supports Used (Mark all that apply)	% Yes	Disability Type			Comparison		Diffs	Disability Severity			Comparison		Diffs
		ID	ASD	Other	F/X2	Sig.		Mild	Moderate	Severe	F/X2	Sig.	
N	3,690	2,323	915	452				699	1,906	1,007			
Local Disability Specific													
A local chapter of The Arc	38%	29%	34%	38%	24.64 ***	a<b,c		33%	39%	40%	7.89 **	a<b,c	
A local community-based disability organization	31%	35%	25%	27%	16.95 ***	a>b,c		28%	33%	30%	2.78		
A local self advocacy group	13%	13%	15%	10%	3.83 *	b>c		13%	13%	12%	.88		
A local therapeutic agency	12%	10%	16%	10%	11.00 ***	b>a,c		13%	11%	13%	2.91		
A faith based organization that supports individuals (families) with disabilities	8%	9%	6%	7%	3.86 *			7%	9%	8%	.93		
My local Protection and Advocacy Center	5%	6%	3%	4%	4.84 **			4%	5%	5%	.48		
A local Easter Seals	5%	5%	4%	6%	1.27			4%	5%	5%	1.66		
A local Center for Independent Living (CIL)	4%	4%	2%	5%	5.18 **	c>b		2%	4%	4%	1.65		
A local United Cerebral Palsy (UCP)	3%	3%	3%	5%	1.64			2%	3%	5%	7.29 **	a,b<c	
Community Resource													
From my school	31%	27%	45%	26%	54.88 ***	b>a,c		34%	32%	30%	1.49		
Action Clubs (i.e., Kiwanis, etc.)	3%	4%	1%	2%	7.05 ***	a>b		2%	4%	2%	4.96 **	c<a,b	
State or National Program													
Special Olympics	25%	31%	16%	15%	56.72 ***	a>b,c		24%	30%	17%	28.14 ***	c<a<b	
My State Developmental Disabilities (DD) Council	12%	13%	10%	12%	2.67			10%	12%	14%	3.17 *	a<c	
Autism Society of America	10%	4%	28%	1%	251.20 ***	b>a>c		10%	10%	10%	.16		
People First / Self Advocates Becoming Empowered	4%	5%	2%	4%	7.46 ***	a>b		4%	4%	3%	2.36		
My State University Center on Developmental Disabilities (UCEDD)	3%	4%	3%	3%	1.89			3%	3%	4%	1.49		
Best Buddies	3%	4%	2%	1%	12.12 ***	a>b,c		4%	4%	2%	2.87	c<a	
I am not receiving services from any of these types of organizations	17%	16%	17%	25%	11.96 ***	c>a,b		19%	15%	20%	6.97 **	b<a,c	

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type

a=Intellectual and Developmental Disabilities (IDD)
 b=Autism Spectrum Disorder (ASD)
 c=Other

Greatest response

Differences: Level of Disability

a=Mild
 b=Moderate
 c=Severe

Table 15 Supports Used by Person with a Disability or the							
Types of Supports Used (Mark all that apply)	Age Group				Comparison		Diffs
	0-13	14-26	27-39	40+	F/X2	Sig.	
N	873	1,132	528	419			
Local Disability Specific							
A local chapter of The Arc	38%	37%	32%	33%	2.33		
A local community-based disability organization	31%	33%	30%	28%	1.27		
A local self advocacy group	16%	12%	10%	14%	3.46 *	c<a,b,d	
A local therapeutic agency	11%	11%	13%	13%	1.64		
A faith based organization that supports individuals (families) with disabilities	7%	9%	9%	9%	0.52		
My local Protection and Advocacy Center	5%	5%	5%	4%	0.54		
A local Easter Seals	6%	5%	4%	3%	1.33		
A local Center for Independent Living (CIL)	3%	3%	3%	4%	0.09		
A local United Cerebral Palsy (UCP)	3%	3%	5%	3%	1.28		
Community Resource							
From my school	32%	27%	34%	38%	7.45 ***	b<a,c,d	
Action Clubs (i.e., Kiwanis, etc.)	3%	4%	2%	3%	0.59		
State or National Program							
Special Olympics	25%	27%	25%	22%	1.16		
My State Developmental Disabilities (DD) Council	14%	14%	12%	7%	5.12 **	d<a,b,c	
Autism Society of America	11%	9%	10%	9%	1.65		
People First / Self Advocates Becoming Empowered	4%	4%	4%	2%	1.06		
My State University Center on Developmental Disabilities (UCEDD)	5%	4%	3%	2%	2.44		
Best Buddies	3%	4%	3%	1%	2.11		
I am not receiving services from any of these types of organizations	17%	18%	16%	21%	2.02		

If at least one item was checked, non-responses were code

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type

a=Intellectual and Developmental Disabilities (IDD)

b=Autism Spectrum Disorder (ASD)

c=Other

Differences: Age of PWD

a=13-17 years

b=18-26 years

c=27-39 years

d=40+ years

Table 16: Changes in availability of supports and services

Support Change	N/ % yes	Disability Type			Compare		Diffs	Level of Disability			Compare		Diffs
		ID	ASD	Other	F/X2	Sig.		Mild	Moderate	Severe	F/X2	Sig.	
Are support services in your community:	3,046	1948	728	356				520	1569	871			
Decreasing	62%	63%	61%	62%	1.88			54%	60%	70%	15.64	***	c<b<a
Staying about the same	31%	31%	30%	32%				37%	33%	25%			
Increasing	7%	6%	9%	5%				9%	7%	6%			
If "decreasing," how has life changed due to the loss of services? (Mark all that apply) (% Yes)	1,897	1,197	471	229				289	965	589			
Family Impacts													
We are paying for services out-of-pocket	47%	44%	55%	47%	9.27	***	c,a<b	52%	46%	47%	1.61		
My family is providing more support than they used to.	41%	41%	38%	45%	1.50			35%	42%	43%	3.00	*	a<b,c
Someone in my family had to quit their job to support the needs of our family member.	20%	17%	28%	22%	12.70	***	c,a<b	15%	18%	26%	9.98	***	a,b<c
We lost our paid support person because there were no funds to pay for them.	9%	9%	9%	10%	0.18			9%	9%	10%	0.50		
Individual Impacts													
Schools have cut back on services like physical therapy, occupational therapy, and speech therapies	43%	40%	55%	36%	17.79	***	c,a<b	43%	44%	43%	0.23		
They are not able to go outside the home as much as they used to do.	29%	31%	22%	31%	7.72	***	b<a,c	17%	24%	41%	36.30	***	a<b<c
They don't get to see friends as much anymore.	24%	26%	18%	26%	5.43	**	b<a,c	19%	24%	28%	4.41	*	a<c
They don't get to choose what they want to do as much as they used to.	23%	25%	16%	25%	9.33	***	b<a,c	19%	23%	23%	1.07		
They don't talk to as many people as they used to.	18%	19%	17%	17%	0.56			16%	17%	21%	2.19		
They have had hours cut at their job, so they are not working as much.	10%	12%	6%	8%	9.72	***	b,c<a	11%	13%	5%	11.47	***	c<a,b
They no longer have access to transportation services to take them places.	9%	10%	6%	10%	5.04	**	b<a,c	10%	9%	8%	0.44		
Day care/ before school/after-school care has closed or shut down	9%	8%	12%	9%	2.95			9%	9%	10%	0.45		
They no longer have a job.	7%	7%	4%	11%	6.05	**	a,b<c	10%	7%	5%	4.08	*	c<a
They don't visit the doctor as often, even if they need to	7%	7%	7%	4%	1.42			5%	7%	7%	0.87		
They no longer have a job coach.	6%	8%	3%	6%	7.82	***	b,c<a	5%	8%	4%	4.79	**	c<b
They eat less.	3%	3%	4%	4%	0.61			4%	2%	4%	2.56		

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type

a=Intellectual and Developmental Disabilities (IDD)
 b=Austim Spectrum Disorder (ASD)
 c=Other

No age differences noted

Greatest response

Differences: Level of Disability

a=Mild
 b=Moderate
 c=Severe

Support for caregivers to plan and get needed services	N	0	1	2	3	Mean	Disability Type			F/X2	Sig.	Diffs
		SD	D	A	SA		ID	ASD	Other			
I am connected to friends or other families connected to disabilities	3,617	8%	17%	48%	28%	1.96	2.04	1.84	1.83	24.93	***	c,b<a
I know how to find out if the person I care for can get disability benefits	3,511	10%	21%	51%	19%	1.78	1.89	1.54	1.76	51.37	***	b<c<a
I know whether or not the person I care for can get disability benefits	3,555	11%	21%	49%	20%	1.77	1.88	1.46	1.80	73.00	***	b<c,a
I know where to get help for what the person I care for needs	3,694	14%	30%	43%	13%	1.54	1.63	1.31	1.53	43.86	***	b<c<a
I know how to get transportation for the person I care for when they need it	3,143	16%	31%	41%	13%	1.51	1.59	1.28	1.55	31.86	***	b<c,a
I have enough information to make good choices about housing options	3,043	23%	36%	28%	12%	1.29	1.37	1.03	1.34	32.43	***	b<c,a
I get enough help in planning for the future	3,541	24%	41%	28%	8%	1.19	1.28	0.94	1.19	46.89	***	b<c,a

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Between Group Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Austim Spectrum Disorder (ASD)
c=Other

Support for caregivers to plan and get needed services	Level of Disability			F/X2	Sig.	Diffs	Age Group				F/X2	Sig.	Diffs
	Mild	Moderate	Severe				0-13	14-26	27-29	40+			
I am connected to friends or other families connected to disabilities	1.96	1.97	1.95	0.24			1.99	1.99	2.00	1.87	2.55		
I know how to find out if the person I care for can get disability benefits	1.70	1.78	1.84	5.11	**	a<c	1.80	1.80	1.86	1.69	2.95	*	d<a,b,c
I know whether or not the person I care for can get disability benefits	1.65	1.75	1.86	11.67	***	a<b<c	1.77	1.80	1.84	1.68	2.69		
I know where to get help for what the person I care for needs	1.56	1.51	1.59	3.02			1.52	1.57	1.60	1.49	1.59		
I know how to get transportation for the person I care for when they need it	1.51	1.51	1.53	0.16			1.49	1.53	1.63	1.51	2.14		
I have enough information to make good choices about housing options	1.39	1.25	1.32	3.99	*	b<a	1.30	1.28	1.36	1.29	0.76		
I get enough help in planning for the future	1.26	1.16	1.18	3.35	*	b<a	1.18	1.17	1.30	1.20	2.47		

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Between Group Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Austim Spectrum Disorder (ASD)
c=Other

Greatest response
Differences: Level of Disability
a=Mild
b=Moderate
c=Severe

Differences: Age of PWD
a=birth-13 years
b=14-26 years
c=27-39 years
d=40+ years

Table 18a: Special equipment, technology or assistive devices used/needed

Technology & Assistive Device Needs	% / N	Disability Type			Comparison		Diffs	Level of Disability			Comparison		Diffs
		ID	ASD	Other	F/X2	Sig.		Mild	Moderate	Severe	F/X2	Sig.	
Use this now: (Mark all that apply)	1,872	1165	352	313				310	885	597			
Cell phone	47%	45%	52%	39%	5.73	**	c<b	67%	54%	22%	121.78	***	c<b<a
Computer/software	32%	30%	40%	28%	8.42	***	a,c<b	37%	34%	24%	11.10	***	c<b<a
Wheelchair, cart, scooter	28%	27%	5%	61%	147.72	***	b<a<c	6%	16%	59%	281.47	***	a<b<c
Knee/ankle braces/orthotics	22%	24%	7%	35%	40.80	***	b<a<c	13%	19%	33%	33.44	***	a<b<c
Vehicle big enough to safely transport wheelchair/scooter	17%	16%	2%	40%	98.76	***	b<a<c	13%	19%	33%	141.76	***	a<b<c
Exercise equipment	16%	17%	14%	14%	1.02			18%	16%	14%	1.21		
Ramp for home	15%	13%	1%	40%	120.19	***	b<a<c	3%	8%	32%	108.69	***	a<b<c
Home modifications for accessibility	14%	13%	3%	30%	55.84	***	b<a<c	4%	9%	27%	74.76	***	a<b<c
Communication board device	13%	11%	17%	15%	6.24	**	a<c	2%	10%	22%	47.82	***	a<b<c
Picture communication software (reading and writing for non-readers)	11%	11%	15%	7%	5.62	*	c<b	5%	10%	16%	14.84	***	a<b<c
Audio books	11%	11%	9%	13%	1.38			9%	9%	13%	2.89		
Vision assistance	10%	11%	5%	15%	8.56	***	b<a,c	9%	12%	22%	2.81		
Lift/carrier to safely transport wheelchairs/scooters in cars	10%	8%	1%	26%	74.05	***	b<a<c	2%	4%	22%	79.44	***	a,b<c
Walker/cane	10%	9%	3%	20%	29.33	***	b<c	5%	9%	14%	10.96	***	a,b<c
Railing/bar/other nonmechanized assist	10%	11%	1%	15%	22.76	***	b<a<c	3%	9%	14%	14.47	***	a<b<c
Hearing assistance or hearing aid	7%	8%	4%	9%	4.56	*	b<a,c	9%	8%	5%	3.99		
Lifts/chairs/other mechanized assists	7%	6%	1%	18%	39.58	***	b<a<c	2%	3%	16%	60.95	***	a,b<c
Video communications	6%	5%	7%	4%	1.15			6%	6%	5%	1.05		
Portable GPS guides	4%	3%	6%	3%	3.14	*	c<b	6%	4%	2%	3.53		
Smart home technology	3%	3%	2%	2%	0.40			2%	2%	3%	0.08		
Guide animal	2%	1%	2%	5%	10.11	***	a,b<c	1%	2%	3%	2.45		
Prosthetics	1%	1%	1%	2%	0.82			0%	1%	2%	1.30		

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Austim Spectrum Disorder (ASD)
c=Other

Greatest response
The only age difference was parents of adults ages 40 and older were more likely to report having portable GPS than parents of younger adults (8% vs 2%).

Differences: Level of Disability
a=Mild
b=Moderate
c=Severe

Table 18b: Special equipment, technology or assistive devices used/needed

Technology & Assistive Device Needs	% / N	Disability Type			F/X2	Sig.	Diffs	Disability Type			F/X2	Sig.	Diffs	Age Group				F/X2	Sig.	Diffs
		ID	ASD	Other				Mild	Moderate	Severe				0-13	14-26	27-39	40+			
N	3,753	1,918	710	389				586	1,522	839				695	905	447	354			
I need special equipment, technology or assistive devices	35%	32%	37%	49%	20.00 ***	a<b,c		22%	30%	55%	111.37 ***	a<b<c		37%	32%	37%	40%	2.84 *		b<d
I need this but don't have it now: (All that apply)	1,755	1,015	431	284				246	839	608				271	768	264	92			
Computer/software	40%	39%	45%	34%	4.34 *	c<b		46%	39%	38%	2.38			38%	40%	36%	42%	0.60		
Exercise equipment	38%	37%	39%	43%	1.82			34%	39%	38%	1.12			45%	35%	35%	48%	4.43 **		a,b<d
Picture communication software (reading and writing for non-readers)	35%	38%	37%	24%	10.39 ***	c<a,b		22%	35%	42%	14.75 ***	a<b,c		32%	35%	35%	46%	1.96 *		a<d
Smart home technology	33%	31%	33%	37%	2.01			25%	32%	36%	4.72 **	a<b,c		32%	33%	30%	35%	0.51		
Audio books	27%	28%	27%	26%	0.14			27%	36%	25%	1.11			25%	27%	26%	32%	0.55		
Communication board device	25%	26%	27%	18%	5.09 **	c<a,b		6%	20%	39%	65.13 ***	a<b<c		23%	25%	27%	35%	1.95		
Home modifications for accessibility	21%	22%	8%	40%	55.29 ***	b<a<c		10%	13%	37%	76.27 ***	a,b<c		20%	21%	22%	23%	0.11		
Portable GPS guides	19%	17%	27%	12%	14.80 ***	a,c<b		23%	22%	12%	13.44 ***	c<a,b		19%	17%	23%	22%	1.66		
Cell phone	16%	15%	18%	16%	1.09			20%	20%	8%	20.83 ***	c<a,b		14%	15%	15%	19%	0.32		
Video communications	15%	14%	17%	14%	0.96			11%	14%	16%	2.31			13%	14%	14%	26%	3.56 *		a,b,c<d
Guide animal	12%	11%	15%	14%	3.18 *	ns		11%	13%	12%	0.31			11%	12%	14%	20%	1.75 *		a<d
Lift/carrier to safely transport wheelchairs/scooters in cars	12%	11%	3%	23%	35.56 ***	b<a<c		4%	6%	20%	60.89 ***	a,b < c		11%	11%	13%	16%	0.87		
Vehicle big enough to safely transport wheelchair/scooter	11%	11%	4%	22%	29.25 ***	b<a<c		4%	6%	20%	43.15 ***	a,b<c		11%	11%	13%	14%	0.59		
Lifts/chairs/other mechanized assists	11%	11%	2%	24%	42.27 ***	b<a<c		2%	5%	22%	66.03 ***	a,b<c		9%	11%	12%	17%	1.58 *		a<d
Railing/bar/other nonmechanized assist	11%	12%	4%	16%	14.62 ***	b<a,c		6%	8%	16%	13.71 ***	a,b<c		9%	10%	11%	14%	0.60		
Ramp for home	10%	10%	4%	16%	12.72 ***	b<a<c		4%	5%	18%	41.01 ***	a,b<c		8%	10%	11%	12%	0.70		
Vision assistance	9%	10%	4%	11%	6.80 **	b<a,c		7%	11%	11%	3.82			8%	8%	8%	15%	1.90 *		a,b,c<d
Knee/ankle braces/orthotics	6%	7%	5%	5%	2.42			4%	7%	6%	0.74			7%	5%	6%	8%	0.86		
Wheelchair, cart, scooter	5%	5%	3%	7%	4.08 *	b<c		3%	4%	7%	4.64 **	a,b<c		4%	5%	5%	3%	0.27		
Hearing assistance or hearing aid	4%	5%	4%	3%	1.72			7%	4%	4%	2.37			3%	4%	7%	3%	1.66		
Walker/cane	2%	2%	1%	4%	3.56 *	b<c		1%	2%	2%	0.62			1%	3%	2%	2%	0.69		
Prosthetics	1%	1%	2%	1%	0.20			2%	1%	1%	0.49			0%	1%	3%	5%	5.67 ***		a,b,c<d
Reasons person doesn't have needed equipment (Mark all that apply)	1,989	1,173	505	311				290	964	695				304	890	307	107			
Can't afford it.	67%	66%	74%	65%	5.95 **	c,a < b		66%	68%	67%	0.18			75%	65%	66%	62%	3.75 *		a>d
Insurance declined it.	16%	15%	13%	26%	13.96 ***	a,b<c		10%	14%	22%	13.78 ***	a,b<c		19%	15%	17%	23%	2.20		
Have it, but it's broken/doesn't work.	5%	5%	4%	7%	1.98			5%	4%	6%	2.51			5%	5%	7%	4%	1.12		
Can't afford to fix it.	5%	5%	5%	5%	0.06			4%	4%	6%	2.69			8%	5%	3%	6%	3.05		
On a waiting list for it.	4%	4%	4%	5%	0.09			3%	4%	6%	3.67 *	a<c		3%	5%	3%	7%	1.43		
Don't know how to use it.	4%	4%	5%	4%	0.46			3%	5%	4%	0.95			6%	4%	4%	7%	1.47		
Used it for a while, but it didn't really help.	4%	4%	3%	3%	2.00			2%	3%	5%	4.31 *	a<c		3%	4%	3%	4%	0.48		
Not comfortable using it.	3%	3%	3%	3%	0.18			2%	3%	4%	1.53			3%	3%	5%	8%	2.36 *		a,b<d
It is on order, but it hasn't arrived yet.	3%	3%	1%	6%	8.30 ***	a,b<c		2%	2%	4%	3.56			1%	3%	3%	5%	1.78		
Doctor says it is not needed.	0%	0%	0%	0%	0.35			0%	0%	0%	0.90			0%	0%	0%	0%			
Never tried to get it.	16%	17%	13%	16%	1.98			19%	17%	14%	2.33			14%	17%	15%	21%	1.00		
Don't know where to get it.	10%	29%	27%	28%	0.21			27%	29%	27%	0.68			28%	28%	25%	34%	1.12		
Other (please specify)	14%	16%	13%	12%	4.31			16%	12%	16%	3.60 *	a<c		11%	15%	18%	12%	2.34		

If at least one item was checked, non-responses were coded as unchecked.

ns followup tests failed to show significant group differences

Significance *** p < .001, ** p < .01, * p < .05

Between Group Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Autism Spectrum Disorder (ASD)
c=Other

Greatest response
Between Group Differences: Level of Disability
a=Mild
b=Moderate
c=Severe

Between Group Differences: Age of PWD
a=0-13 years
b=14-26 years
c=27-39 years
d=40+ years

Table 19a: Job characteristics for people with disabilities who currently work

Job Characteristics	N/%	Disability Type			F/X2	Sig.	Diffs	Level of Disability			F/X2	Sig.	Diffs
		ID	ASD	Other				Mild	Moderate	Severe			
Sample size	2,529	1,338	539	291				442	1,133	595			
Parent reports their adult family member has a job	15%	15%	16%	14%	0.19			16%	16%	13%	1.79		
Where does the person work? (Mark all that apply)													
A regular job in the community	7%	7%	6%	7%	0.64			6%	8%	6%	2.83		
Sheltered Workshop	6%	5%	8%	6%	2.58			7%	6%	6%	0.52		
Enclave Setting (e.g. work crews made up only of people with disabilities)	3%	3%	3%	3%	0.17			3%	3%	3%	0.17		
Self-Employed	1%	1%	1%	1%	0.36			1%	1%	1%	0.65		
What kind of work do they do? (Mark all that apply)													
Piece work, assembly, packaging & shipping	32%	30%	37%	25%	3.05 *	c<b		21%	57%	22%	1.28		
Facility maintenance, janitorial, cleaning	19%	20%	19%	17%	0.29			18%	20%	19%	0.16		
Office work, reception, filing, shredding, recycling, mail delivery	16%	16%	17%	17%	0.12			14%	18%	14%	0.78		
Food preparation, bussing tables	14%	13%	12%	26%	7.59 **	a,b<c		16%	14%	15%	0.31		
Retail, working at a business selling things	9%	10%	6%	12%	1.89			9%	8%	12%	0.88		
Landscaping, gardening	8%	8%	7%	8%	0.05			5%	8%	8%	0.67		
Animal care	4%	4%	3%	5%	0.86	b<c		2%	3%	3%	0.10		
Child care	3%	4%	2%	0%	3.50 *	c<a		2%	4%	3%	0.64		
Professional work, project assistance, project management, self-advocacy, public speaking#	2%	2%	3%	3%	0.51			1%	2%	3%	0.40		
They own and operate a business, making/selling items or services	2%	3%	1%	2%	1.36			3%	2%	3%	0.25		
Other (please specify)	23%	23%	21%	21%	0.36			26%	21%	21%	0.80		
Does the person receive competitive wages?	48%	51%	44%	43%	0.89			39%	52%	47%	2.25	a<b,c	
Do you agree that: (Mark all that apply)													
They like what they do at their job.	82%	82%	80%	83%	0.15			80%	84%	78%	0.91		
They are satisfied with their work hours.	78%	74%	82%	88%	2.84			76%	79%	75%	0.36		
They are satisfied with their wages.	69%	71%	67%	65%	0.51			62%	74%	66%	2.45		
They earn at least minimum wage.	57%	60%	53%	54%	4.41			46%	63%	53%	4.09 *	a<b	
They can set and pursue goals related to their employment.	49%	50%	46%	48%	0.21			48%	49%	51%	0.06		
They can get job training when they want it.	48%	48%	38%	65%	4.87 **			49%	46%	49%	0.18		
They are able to obtain assistance in finding and keeping employment when they need it.	48%	48%	44%	54%	0.63			48%	46%	49%	0.08		
They have benefits from their employer like other employees without disabilities.	32%	33%	27%	40%	1.44			31%	37%	23%	2.66		
They can advance into a position with more responsibilities at their job.	28%	26%	28%	37%	1.08			31%	28%	24%	0.48		

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Austim Spectrum Disorder (ASD)
c=Other

There were no significant differences on these items for adults by age group (18-30, 31-50, 51-79)

Greatest response
Differences: Level of Disability
a=Mild
b=Moderate
c=Severe

Table 19b: Employment of people with disabilities																		
Employment Beliefs for Caregivers	N	% Yes	Disability Type			Comparison		Level of Disability			Comparison		Age Group				Comparison	
			ID	ASD	Other	X2	Sig.	Mild	Moderate	Severe	X2	Sig.	0-13	14-26	27-39	40+	X2	Sig.
People with IDD should be paid at least minimum wage for the work they do, even if they are not as productive as a worker without a disability	1,827	82%	83%	83%	80%	1.58		81%	82%	83%	0.79		81%	80%	83%	6.63		
Caregiver preferred employment location for person (asked of all ages)	2,825		1,502	621	326			485	1,254	653			625	890	413	301		
A Regular Job in the Community		63%	65%	60%	59%	13.09 *		61%	63%	64%	3.34		66%	62%	62%	59%	19.39 *	
Sheltered Workshop		19%	18%	21%	18%			21%	19%	17%			17%	17%	21%	24%		
Enclave Setting		12%	11%	13%	16%			12%	12%	13%			10%	14%	12%	12%		
Self-Employment		7%	7%	6%	8%			7%	7%	7%			8%	8%	6%	5%		
The person is/was satisfied with work setting (% Satisfied):																		
Regular job in the community	250	84%	<div style="border: 1px solid black; padding: 5px;"> <p>Sample sizes for these analyses were too small to compare disability groups, types or ages</p> </div>															
Self-Employed	26	81%																
Enclave Setting	111	74%																
Sheltered Workshop	226	68%																
The person is/was satisfied with type of work (% Satisfied):																		
Self-Employed	18	79%	<div style="border: 1px solid black; padding: 5px;"> <p>If at least one item was checked, non-responses were coded as unchecked. Significance *** p < .001, ** p < .01, * p < .05 Greatest response</p> </div>															
Regular job in the community	166	69%																
Enclave Setting	81	65%																
Sheltered Workshop	155	42%																

Differences: Level of Disability
a=Mild
b=Moderate
c=Severe

Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Austim Spectrum Disorder (ASD)
c=Other

Effects of Caregiving	0	1	2	Mean	Disability Type			F/X2	Sig.	Diffs
	Not at all	Sometimes	Most of the time		ID	ASD	Other			
	Physical strain/fatigue	12%	54%		34%	1.22	1.15			
Financial strain	19%	46%	35%	1.16	1.08	1.38	1.19	54.48 ***	a<c<b	
Emotional upset, guilt	19%	59%	22%	1.03	0.96	1.22	1.05	50.97 ***	a<c<b	
Stress in close personal relationships	24%	52%	25%	1.01	0.93	1.21	1.02	48.80 ***	a<c<b	
Feelings of being underappreciated	29%	48%	23%	0.95	0.89	1.08	0.98	23.16 ***	a<c<b	
Reluctance to ask for help	26%	53%	21%	0.94	0.89	1.06	1.01	22.61 ***	a<c,b	
My own health issues	28%	53%	19%	0.92	0.86	1.02	0.97	18.51 ***	a,c<b	
Interference with work	30%	51%	20%	0.90	0.84	1.07	0.89	32.01 ***	a,c<b	
Loneliness	34%	48%	18%	0.83	0.76	1.02	0.84	40.97 ***	a<c<b	
Concern about how to best support and explain roles to siblings of the person with a disability	39%	43%	18%	0.79	0.74	0.94	0.74	24.22 ***	a,c<b	
				% Yes						
Caregiver health Status				3,441	2,164	840	437			
Excellent				16%	18%	12%	14%			
Good				54%	54%	54%	52%			
Fair				26%	28%	30%	24%			
Poor				4%	4%	4%	6%			
Mean				2.82	2.86	2.73	2.74	11.74 ***	b,c<a	
Caregiver Stress Level				3,442	2,162	845	435			
Not stressed				7%	9%	3%	7%			
Somewhat stressed				51%	54%	42%	52%			
Very stressed				30%	27%	37%	30%			
Extremely stressed				12%	11%	18%	11%			
Mean				1.47	1.38	1.69	1.45	45.32 ***	a,c<b	

If at least one item was checked, non-responses were coded as unchecked.

ns followup tests failed to show significant group differences

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Austim Spectrum Disorder (ASD)
c=Other

Table 20: Physical and emotional effects of caregiving													
Effects of Caregiving	Level of Disability			F/X2	Sig.	Diffs	Age Group - Mean				F/X2	Sig.	Diffs
	Mild	Moderate	Severe				0-13	14-26	27-39	40+			
Physical strain/fatigue	1.01	1.18	1.42	86.14	***	a<b<c	1.22	1.19	1.21	1.22	0.44		
Financial strain	1.03	1.16	1.25	16.23	***	a<b<c	1.23	1.12	1.19	1.12	4.47	**	b,d<a,c
Emotional upset, guilt	0.93	1.03	1.09	12.34	***	a<b,c	1.07	1.00	1.09	1.01	2.77		
Stress in close personal relationships	0.89	1.00	1.10	17.44	***	a<b<c	1.03	0.99	1.04	1.00	1.00		
Feelings of being underappreciated	0.88	0.95	0.99	4.78	**	a<c	0.98	0.89	0.97	0.95	2.93		
Reluctance to ask for help	0.89	0.93	1.01	7.28	***	a,b<c	0.97	0.92	0.92	0.94	0.90		
My own health issues	0.76	0.89	1.06	38.62	***	a<b<c	0.94	0.89	0.86	0.96	2.45		
Interference with work	0.78	0.88	1.02	23.36	***	a<b<c	0.96	0.88	0.88	0.86	2.45		
Loneliness	0.72	0.82	0.93	18.58	***	a<b<c	0.85	0.80	0.86	0.84	1.47		
Concern about how to best support and explain roles to siblings of the person with a disability	0.76	0.79	0.79	0.38			0.80	0.74	0.82	0.82	1.76		
Caregiver health Status	625	1,722	922				428	1609	524	170			
Excellent	21%	16%	14%				18%	15%	18%	16%			
Good	55%	54%	53%				52%	52%	52%	54%			
Fair	21%	27%	28%				27%	26%	26%	25%			
Poor	3%	4%	6%				4%	4%	4%	5%			
Mean	2.93	2.81	2.74	29.44	***	b,c<a		2.81	2.84	2.81	0.27		
Caregiver Stress Level	658	1,807	981				2.83	1610	524	170			
Not stressed	11%	7%	6%				7%	8%	7%	7%			
Somewhat stressed	55%	52%	46%				47%	54%	48%	51%			
Very stressed	26%	29%	32%				32%	27%	33%	29%			
Extremely stressed	7%	12%	17%				13%	11%	12%	14%			
Mean	1.30	1.46	1.59	26.87	***	a<b<c	1.51	1.41	1.50	1.50	3.45	*	

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Greatest response
Differences: Level of Disability
a=Mild
b=Moderate
c=Severe

Differences: Age of PWD
a=birth-13 years
b=14-26 years
c=27-39 years
d=40+ years

Table 21: Social and family outcomes for caregivers

Effects of Caregiving	N	Disability Type				Mean	Disability Type				F/X2	Sig.	Diffs	Level of Disability			F/X2	Sig.	Diffs
		0	1	2	3		ID	ASD	Other	Mild				Moderate	Severe				
		SD	D	A	SA														
I don't have enough time for myself due to my caregiving responsibilities.	3,272	7%	30%	44%	19%	1.75	1.68	1.92	1.76	23.78 ***	a,c<b	1.58	1.72	1.92	32.70 ***	a<b<c			
I have more care giving responsibilities than I can handle comfortably.	3,287	10%	44%	34%	12%	1.49	1.43	1.65	1.46	21.76 ***	a,c<b	1.30	1.47	1.65	34.07 ***	a<b<c			
I often feel guilty about care given to child with disabilities vs. children that do not have disabilities.	2,626	17%	35%	34%	13%	1.43	1.38	1.53	1.50	6.93 ***	a<c,b	1.08	1.00	0.86	0.68				
Afterschool care for a child with disabilities is easy to find	1,953	55%	36%	7%	3%	0.58	0.60	0.54	0.55	1.48		0.68	0.60	0.50	7.01 ***	c<a			
I have a healthy retirement account	3,222	40%	33%	23%	4%	0.92	1.00	0.75	0.86	23.95 ***	b<c<a	1.01	0.94	0.85	6.12 **	c<a			
I have been able to pursue my own work/career goals to the fullest extent	3,169	37%	30%	26%	5%	0.98	1.07	0.77	0.94	33.40 ***	b<c<a	1.08	1.00	0.86	12.23 ***	c<b<a			
My family goes on a nice vacation every year	3,298	39%	30%	26%	5%	0.98	1.06	0.85	0.89	17.81 ***	b,c<a	1.13	1.00	0.85	17.04 ***	c<b<a			
I have an active and enjoyable social life	3,353	22%	39%	33%	5%	1.21	1.32	0.98	1.16	48.28 ***	b<c<a	1.36	1.23	1.09	18.88 ***	c<b<a			
Having a child with disabilities did not adversely affect my marriage	3,047	26%	32%	29%	13%	1.29	1.37	1.08	1.30	24.29 ***	b,c<a	1.50	1.28	1.15	22.15 ***	c<b<a			
I usually get a restful night's sleep.	3,388	19%	35%	41%	6%	1.35	1.42	1.19	1.32	22.85 ***	b<c<a	1.50	1.37	1.21	24.21 ***	c<b<a			
I have a good balance between work, family and personal relationships.	3,288	14%	42%	38%	6%	1.35	1.43	1.15	1.34	36.95 ***	b<c<a	1.49	1.36	1.24	19.59 ***	c<b<a			
I feel in control of the important things in my life.	3,395	10%	34%	50%	7%	1.54	1.62	1.34	1.56	40.86 ***	b<a,c	1.64	1.53	1.49	7.05 ***	c,b<a			
I am doing a good job of meeting work, family, and personal responsibilities.	3,307	9%	34%	51%	6%	1.55	1.62	1.37	1.57	33.16 ***	b<a,c	1.62	1.55	1.51	3.66 *	c<a			

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Autism Spectrum Disorder (ASD)
c=Other

Greatest response
No age differences noted

Differences: Level of Disability
a=Mild
b=Moderate
c=Severe

Table 22: Civic and social outcomes of caregiving

Outcomes for Caregivers	% Yes/ N	Disability Type			F/X2	Sig.	Diffs	Level of Disability			F/X2	Sig.	Diffs
		ID	ASD	Other				Mild	Mod	Severe			
	4,557	990	348	193				900	2,318	1,250			
I have developed new values about life and what is important	62%	64%	60%	56%	13.94	***	c<a	56%	62%	64%	7.67	***	a<b,c
I am more aware of policy issues relating to disability	52%	55%	48%	49%	19.84	***	b,c<a	47%	53%	55%	6.30	**	a<b,c
I have found new friends that are also connected to disability	42%	46%	38%	34%	39.68	***	b,c<a	39%	43%	41%	1.82		
I am more involved in advocacy efforts	42%	45%	40%	34%	27.34	***	c<b<a	37%	42%	44%	5.81	**	a<b,c
I appreciate others more than I used to	39%	41%	36%	36%	9.09			37%	39%	40%	0.76		
I feel fortunate to have this life experience	38%	42%	29%	32%	66.23	***	b,c<a	39%	38%	37%	0.20		
My family relationships have been strengthened	34%	35%	31%	32%	7.70			33%	34%	33%	0.66		
I am more involved in local non-profit activities	32%	36%	27%	24%	47.87	***		30%	33%	31%	5.81	**	a<b,c
I have become more spiritual or religious	30%	31%	26%	30%	8.01			30%	29%	31%	0.65		
I spend more time at home invested in family-oriented	28%	29%	29%	25%	5.20			27%	29%	29%	0.51		
I vote more regularly	26%	27%	23%	24%	8.22			22%	26%	27%	4.07	*	a<b,c
I take more time to not rush through life	24%	26%	20%	22%	21.73	***	b,c<a	25%	23%	24%	1.68		
I have noticed that people in my community are always happy	22%	26%	11%	20%	109.56	***	b<c<a	20%	23%	20%	1.95		
I have closer ties to people in my community	16%	19%	11%	11%	45.50	***	b,c<a	16%	17%	14%	3.21		
My quality of life has improved	14%	17%	9%	11%	48.36	***	b,c<a	16%	14%	13%	2.28		

Significance *** p < .001, ** p < .01, * p < .05

If at least one item was checked, non-responses were coded as unchecked.

Differences: Disability Type

a=Intellectual and Developmental Disabilities (IDD)
 b=Austim Spectrum Disorder (ASD)
 c=Other

Greatest response

Differences: Level of Disability

a=Mild
 b=Moderate
 c=Severe

Outcomes for Caregivers	Age Group				F/X2	Sig.	Diffs
	0-13	14-26	27-39	40+			
	1,186	1,602	807	618			
I have developed new values about life and what is important	57%	54%	49%	51%	14.71	**	c,d<a
I am more aware of policy issues relating to disability	49%	47%	42%	41%	16.14	***	d<a,b; c<a,b
I have found new friends that are also connected to disability	40%	37%	32%	34%	16.36	***	c<a,b; d<a
I am more involved in advocacy efforts	41%	38%	23%	32%	22.68	***	c,d<a,b
I appreciate others more than I used to	37%	35%	30%	30%	19.34	***	c,d<a,b
I feel fortunate to have this life experience	34%	34%	31%	31%	3.81		
My family relationships have been strengthened	31%	30%	26%	28%	5.15		
I am more involved in local non-profit activities	31%	31%	22%	23%	34.40	***	c,d<a,b
I have become more spiritual or religious	25%	26%	26%	26%	1.06		
I spend more time at home invested in family-oriented	26%	25%	22%	24%	4.01		
I vote more regularly	24%	23%	19%	20%	10.79	**	b<a
I take more time to not rush through life	20%	22%	19%	21%	2.97		
I have noticed that people in my community are always happy	19%	20%	15%	18%	9.07	*	c<b
I have closer ties to people in my community	14%	15%	12%	14%	6.38		
My quality of life has improved	12%	13%	11%	12%	3.09		

Significance *** p < .001, ** p < .01, * p < .05

Differences: Disability Type	Differences Age of Person
a=Intellectual and Developmental Disabilities (IDD)	a=birth-13 years
b=Austim Spectrum Disorder (ASD)	b=14-26 years
c=Other	c=27-39 years
	d=40+ years

Challenges	N	Severity			Mean	Disability Type			Compare		Diffs	Severity			Compare		Diffs
		0	1	2		ID	ASD	Other	F/X2	Sig.		Mild	Moderate	Severe	F/X2	Sig.	
		Not a Problem	Some Problem	Major Problem													
	N					1,492	576	285				313	1,179	806			
Having enough retirement savings	2,928	15%	32%	52%	1.37	1.30	1.53	1.37	25.22 ***	a,c<b	1.26	1.35	1.46	12.73 ***			
Finding non-institutional, community-based care	1,645	18%	31%	51%	1.33	1.28	1.46	1.34	8.30 ***	a<c,b	1.16	1.32	1.40	7.77 ***	a<b,c		
Finding trained and reliable home care providers	2,353	16%	36%	48%	1.31	1.27	1.43	1.30	10.52 ***	a,c<b	1.14	1.29	1.40	15.46 ***	a<b<c		
Finding after school care/summer care	1,898	20%	30%	50%	1.30	1.24	1.42	1.30	11.35 ***	a<c,b	1.20	1.27	1.41	8.16 ***			
Finding affordable residential care	1,057	25%	23%	53%	1.28	1.24	1.39	1.31	3.01		1.07	1.31	1.30	4.84 **	a<b,c		
Overall economic security	2,985	18%	37%	45%	1.27	1.18	1.46	1.31	39.65 ***	a<c<b	1.15	1.25	1.36	12.74 ***	a<b<c		
Being able to go on regular vacations	2,963	22%	32%	47%	1.25	1.17	1.41	1.34	27.93 ***	a,c<b	1.04	1.21	1.44	45.29 ***	a,b<c		
Meeting my personal needs such as personal time, exercise, etc.	2,952	19%	40%	41%	1.22	1.15	1.40	1.21	29.38 ***	a,c<b	1.10	1.19	1.33	17.55 ***	a<b<c		
Having enough money to pay for care	2,627	20%	39%	41%	1.21	1.12	1.43	1.21	42.93 ***	a,c<b	1.12	1.21	1.25	4.50 **	a<b,c		
Balancing other family responsibilities—e.g., children, marriage, housework.	2,970	18%	43%	39%	1.21	1.14	1.40	1.19	35.50 ***	a,c<b	1.10	1.19	1.32	15.27 ***	a<b<c		
Respite care to have time to take care of my own needs	2,604	23%	36%	42%	1.18	1.12	1.32	1.23	17.40 ***	a<c,b	1.00	1.15	1.33	26.64 ***	a<b<c		
Building inclusive friendships for my family member.	2,937	22%	41%	38%	1.16	1.10	1.34	1.05	31.12 ***	a,c<b	1.06	1.17	1.19	4.92 **	a<b,c		
Getting enough rest	2,685	23%	39%	38%	1.15	1.07	1.32	1.21	28.28 ***	a<c<b	0.98	4.40	1.33	37.01 ***	a<b<c		
Adjusting my work schedule, meeting my work responsibilities.	2,495	29%	39%	33%	1.04	0.98	1.17	1.05	13.28 ***	a,c<b	0.90	1.01	1.16	16.46 ***	a<b<c		
Understanding government programs such as Medicare or SSI.	2,942	26%	47%	27%	1.01	0.95	1.16	0.99	23.06 ***	a,c<b	1.03	1.01	0.99	0.55			
Finding out about legal options.	2,798	27%	47%	26%	0.99	0.93	1.13	1.03	19.28 ***	a<c<b	0.99	1.00	0.98	0.28			
Trying to provide care when I have my own health issues	2,305	33%	36%	31%	0.98	0.94	1.05	1.07	5.77 **	a<b,c	0.78	0.94	1.12	25.63 ***	a<b<c		
Emergency Care when I need to care for another family member (i.e., sandwich generation issues)	1,955	37%	32%	32%	0.95	0.91	1.03	1.00	4.22		0.76	0.88	1.13	26.92 ***	a<b<c		
Dealing with break downs in care arrangements.	2,422	32%	44%	24%	0.92	0.89	0.98	1.00	4.47		0.75	0.87	1.08	31.01 ***	a<b<c		
Dealing with dangerous, unwanted, or difficult behaviors of the person that I care for.	2,598	35%	40%	25%	0.89	0.83	1.13	0.66	52.55 ***	c<a<b	0.77	0.88	1.00	12.39 ***	a<b<c		
Day care so I can work	1,861	43%	26%	31%	0.88	0.79	1.04	0.93	15.93 ***	a<c,b	0.70	0.82	1.02	17.04 ***	a<b<c		
Having someone to talk to that understands what I deal with	2,841	39%	36%	25%	0.86	0.80	0.98	0.91	14.31 ***	a<c,b	0.82	0.83	0.93	5.00 **	a,b<c		
Doing end of life planning.	2,214	39%	40%	21%	0.82	0.77	0.99	0.77	17.47 ***	c,a<b	0.67	0.83	0.88	8.86 ***	a<b,c		
Getting cooperation and assistance from other family members.	2,753	42%	34%	24%	0.81	0.76	0.94	0.82	13.45 ***	a<c<b	0.74	0.77	0.93	12.29 ***	a,b<c		
Support for siblings of the individual with a disability	2,309	43%	37%	21%	0.78	0.69	0.99	0.78	30.86 ***	a,c<b	0.74	0.76	0.84	2.65			
Ensuring the safety of the person I care for.	2,849	43%	41%	17%	0.74	0.70	0.87	0.71	14.70 ***	a,b<c	0.60	0.73	0.84	16.78 ***	a<b<c		
Identifying available transportation options.	2,295	45%	37%	18%	0.73	0.73	0.76	0.71	0.54		0.70	0.76	0.69	2.31			
Modifying my home to meet care requirements.	2,019	55%	27%	18%	0.63	0.58	0.58	0.90	21.79 ***	a,b<c	0.35	0.50	0.90	84.77 ***	a<b<c		
Communicating with professional resource providers.	2,709	52%	34%	14%	0.62	0.59	0.70	0.65	5.76 **	a<c,b	0.60	0.62	0.64	0.41			
Finding culturally sensitive resources.	1,916	61%	26%	13%	0.52	0.50	0.59	0.52	2.43		0.63	0.52	0.49	3.87 *	b,c<a		
Night care – for when I work overnight shifts	1,149	68%	12%	20%	0.51	0.47	0.60	0.59	3.30		0.40	0.44	0.66	10.18 ***	a,b<c		
Getting information about the illness/disability of the person I care for.	2,631	71%	20%	10%	0.39	0.36	0.39	0.51	7.18 **	a,b<c	0.42	0.35	0.42	3.41			
Involvement in decisions about the medical treatment of the person I care for.	2,696	70%	22%	8%	0.38	0.35	0.43	0.38	3.99		0.35	0.36	0.41	2.16			

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

ns followup tests failed to show significant group differences

Differences: Disability Type
a=Intellectual and Developmental Disabilities (IDD)
b=Austim Spectrum Disorder (ASD)
c=Other

Greatest response
Differences: Level of Disability
a=Mild
b=Moderate
c=Severe

Challenges	Age Group -Mean				Compare		Diffs
	0-13	14-26	27-39	40+	F/X2	Sig.	
	556	730	330	263			
Having enough retirement savings	1.42	1.36	1.36	1.31	1.91		
Finding non-institutional, community-based care	1.32	1.33	1.28	1.36	0.34		
Finding trained and reliable home care providers	1.36	1.28	1.34	1.27	1.72		
Finding after school care/summer care	1.34	1.26	1.35	1.29	1.18		
Finding affordable residential care	1.26	1.26	1.26	1.34	0.31		
Overall economic security	1.32	1.27	1.24	1.17	3.03	*	d<a,b,c
Being able to go on regular vacations	0.79	0.80	0.77	0.79	1.53		
Meeting my personal needs such as personal time, exercise, etc.	1.26	1.18	1.26	1.2	2.15		
Having enough money to pay for care	1.29	1.16	1.24	1.15	4.63	**	d,b<c,a
Balancing other family responsibilities—e.g., children, marriage, housework.	1.24	1.19	1.22	1.17	0.74		
Respite care to have time to take care of my own needs	1.23	1.15	1.23	1.11	2.69		
Building inclusive friendships for my family member.	1.16	1.19	1.16	1.07	1.94		
Getting enough rest	1.19	1.11	1.19	1.13	1.75		
Adjusting my work schedule, meeting my work responsibilities.	1.07	1.01	1.07	1	1.22		
Understanding government programs such as Medicare or SSI.	1.00	1.00	1.00	1.01	0.03		
Finding out about legal options.	0.95	0.98	0.98	0.99	0.35		
Trying to provide care when I have my own health issues	1.03	0.95	0.97	0.81	1.01		
Emergency Care when I need to care for another family member (i.e., sandwich generation issues)	0.95	0.93	0.97	0.81	1.73		
Dealing with break downs in care arrangements.	0.96	0.9	0.93	0.84	1.64		
Dealing with dangerous, unwanted, or difficult behaviors of the person that I care for.	0.91	0.84	0.94	0.92	2.10		
Day care so I can work	0.94	0.8	0.93	0.8	3.36		
Having someone to talk to that understands what I deal with	0.84	0.88	0.9	0.87	0.56		
Doing end of life planning.	0.84	0.84	0.78	0.76	1.00		
Getting cooperation and assistance from other family members.	0.8	0.81	0.83	0.84	0.23		
Support for siblings of the individual with a disability	0.81	0.71	0.84	0.83	3.47		
Ensuring the safety of the person I care for.	0.71	0.77	0.71	0.69	1.41		
Identifying available transportation options.	0.72	0.75	0.68	0.68	0.95		
Modifying my home to meet care requirements.	0.58	0.62	0.67	0.67	1.03		
Communicating with professional resource providers.	0.62	0.66	0.54	0.69	3.09	*	c<a,b,d
Finding culturally sensitive resources.	0.49	0.56	0.51	0.57	1.12		
Night care – for when I work overnight shifts	0.51	0.5	0.53	0.43	0.36		
Getting information about the illness/disability of the person I care for.	0.38	0.38	0.37	0.4	0.21		
Involvement in decisions about the medical treatment of the person I care for.	0.38	0.35	0.35	0.39	0.49		

If at least one item was checked, non-responses were coded as unchecked.

Significance *** p < .001, ** p < .01, * p < .05

Differences: Age of PWD

a=birth-13 years

b=14-26 years

c=27-39 years

d=40+ years