

FAST

PACER's National Family Advocacy and Support Training Project

2010 FAST FAMILY SUPPORT SURVEY: NATIONAL RESULTS

MARCH 15, 2011

FINAL

Prepared for the PACER Center

by the

Institute on Community Integration

©2011 by PACER Center, Inc. All rights reserved. No portion of this book may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without express written permission of PACER Center, except for brief quotations or personal use.

Paula Goldberg, PACER Center Executive Director
Shauna McDonald, FAST Coordinator

PACER Center, Inc.
8161 Normandale Blvd.
Minneapolis, MN 55437-1044
952.838.9000 Voice
952.838.0190 TTY
952.838.0199 Fax
800.537.2237 Toll-free in Minnesota
888.248.0822 Toll-free nationwide
PACER@PACER.org
PACER.org

The recommended citation for this report is: Larson, S.A., Goldberg, P., McDonald, S., Leuchovius, D., Richardson, V. & Lakin, K.C. (2011). **2010 Fast Family Support Survey: National Results.** Minneapolis: PACER Center; Minneapolis, University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration (UCEDD)

The authors thank John Westerman, Brooke Nelson, Erica Hagelberg and Lynda Anderson for their contributions to this project.

The FAST Project is funded by the Administration on Developmental Disabilities (ADD) as a Project of National Significance. Preparation of this report was supported by a grant from the Administration on Developmental Disabilities (Grant no. 90DN0269) of the U.S. Department of Health and Human Services. The contents of this report do not necessarily reflect an official position of any sponsoring agency.

The University of Minnesota is committed to the policy that all persons shall have equal access to its facilities and employment without regard to race, color, creed, religion, national origin, sex, age, marital status, disability, public assistance status, veteran status, or sexual orientation.

EXECUTIVE SUMMARY

This report summarizes the results of a 2010 national internet survey of 2,416 parents or relatives of children and youth ages 11 years to 39 years with disabilities from 54 states or U.S. territories (See Table 1). Respondents mentioned more than 300 physical, cognitive or health related disabilities as their family member's primary disability. Family members were grouped into three categories: intellectual or developmental disabilities, (IDD; 849 family members), autism spectrum disorders, (ASD; 857 family members), and all other disabilities (OTHER; 710 family members; See Table 2).

A total of 42% of respondents reported household incomes of \$50,000 per year or less, 75% were married or partnered, and 93% reported that they lived in the same home as the child or youth (See Table 3). While 73% of the children and youth were described as white and non-Hispanic, 9% were Spanish/Hispanic/Latino, 8% were Black or African American, and 12% were described as being of another race. Overall, 27% of the respondents ($N = 646$) were from one or more underrepresented group (i.e., they reported incomes of less than \$20,000, a race or ethnicity other than White Non-Hispanic, or a first language other than English).

The characteristics of the child/youth differed for the three disability categories as youth with IDD or ASD reported to be older, more likely to live with the respondent, and lived in communities with higher median family incomes than those with OTHER disabilities. Youth with ASD were more likely to be males and to speak English than the other two groups.

WHAT DID WE ASK ABOUT?

Parents rated the importance of knowing how to get support in 20 areas (See Table 4). They reported whether the family needed but was not receiving help (See Table 5), and the quality of supports they currently received (See Table 6). Families also reported who they asked to find information about supports (See Table 7) and which services they currently received (See Table 8).

WHAT DID WE LEARN?

The full report describes the overall experiences of all families and compares the answers of family members of youth by disability category (IDD, ASD or OTHER), age group (12 to 16 years and 17 to 22 years) and family annual income level (less than \$20,000 per year, \$20,000 to \$50,000 and more than \$50,000).

HOW IMPORTANT IS IT FOR YOU TO KNOW HOW TO GET TRANSITION SUPPORTS?

Most families think knowing how to get information about building lifelong relationships, advocating for the family members' rights, choosing employment supports, preparing to work, finding a job, getting financial assistance, and getting medical care is very important.

Families of youth with ASD or IDD were more likely than families of youth with OTHER disabilities to report that finding information about these topics is very important. Families of youth ages 12 to 16 years reported getting information in these areas to be more important than families of youth ages 17 to 22 years.

WHAT DO FAMILIES NEED THAT THEY DO NOT CURRENTLY GET?

More than a third of all families said they needed but were not getting help for their family member with preparing for healthy, loving adult relationships, preparing others to support their family member, finding and keeping a job, finding housing and support services, obtaining financial assistance, and finding transportation.

Families of youth ages 11 to 16, youth with ASD or OTHER disabilities, and families with lower household incomes were more likely to report unmet needs in these areas than families of older youth, youth with IDD, or families with incomes of greater than \$50,000 per year.

HOW GOOD ARE THE SUPPORTS THAT FAMILIES CURRENT GET?

Overall, families reported that their current services were of fair quality. The only service rated as good was support for advocating for the family member's rights. None of the services were rated as very good. Services to help the family member find a job and to find postsecondary education were the lowest rated supports.

Service quality varied in several ways. In four areas families of youth with OTHER disabilities said they were getting higher quality supports. In four areas families of youth with IDD said they were getting higher quality support. In one area families of youth with ASD said they were getting higher quality support than those in the other groups. In three areas, families of younger youth reported receiving higher quality supports, and in ten areas families with the lowest annual incomes reported receiving higher quality supports.

WHERE DO FAMILIES GO FOR INFORMATION ABOUT TRANSITION SUPPORTS?

More than half of the families reported getting information about transition supports from advocacy organizations, teachers or other school staff, books, television or radio, or from family members or friends. Families of youth with ASD were more likely to contact advocacy organizations, read books or watch television reports, or to use the internet than families of youth with IDD or OTHER disabilities.

In general, families of youth with OTHER disabilities were less likely to use the listed resources. Families with the lowest incomes were less likely to get information from advocacy organizations but more likely to get information from support groups, workshops or disability organizations. Families of older youth were more likely to use 12 of the 26 types of resources than families of younger youth.

WHAT SERVICES DO FAMILIES CURRENTLY GET?

Nearly two-thirds of families reported their youth was currently attending a Kindergarten through Grade 12 (K-12) school. Between 40% and 50% of families reported having health insurance, receiving case management, or receiving Medicaid funded services.

Families of youth with OTHER disabilities were less likely than families with ASD or IDD disabilities to report using the most common services. Youth with ASD or OTHER disabilities were nearly twice as likely as families of youth with IDD to receive behavioral or mental health services. Families of younger youth were more likely to receive services from a K-12 school, health insurance, behavioral or mental health services and therapy services than families of older youth. Families of older youth were more likely to get case management or Medicaid funded services. Families with the highest incomes were more likely to have health insurance. Families with incomes of \$20,000 to \$50,000 were most likely to get case management, and families with incomes of \$50,000 or less were more likely to get Medicaid funded supports.

SO WHAT SHOULD WE DO ABOUT IT?

Families of transition age youth are very likely to report that getting information about various transition topics is important. However, many have currently unmet support needs. Families seek information from a variety of sources. Transition support information should be available in a variety of formats from a variety of information sources. Parent Centers need to find ways to help families with the many unaddressed support needs for youth with disabilities and their family members they reported. Some needs, such as the need for help preparing youth for healthy, loving adult relationships, and preparing for and obtaining employment are addressed in the FAST projects curriculum, while other needs are not.

The most often used sources of information reported by families about transition supports were advocacy organizations, teachers or other school staff, books, television or radio, and family members or friends. Neither Parent Information Centers nor programs funded by the Administration for Developmental Disabilities (such as the University Centers of Excellence in Developmental Disabilities, Developmental Disability Councils, and Protection and Advocacy Organizations) were among the top five information sources (with the exception of internet based information).

About 628 respondents specifically identified Parent Centers as a source of transition information. Given the survey methodology (with Parent Information Centers having a goal to recruit 1,000 families from amongst those trained in the project) it appears that at least some parents who were trained by parent information centers identified those centers in another category (such as advocacy organization, disability organization or community organization). This is further supported by the fact that all of the respondents heard about the survey either directly or indirectly from the parent center in their state or from an affiliated organization. Given the large number of families trained in 2010 by the parent centers on the FAST curricula, the approach of working through a network of Parent Information Centers is an effective way to get information out to parents on these topics.

BACKGROUND

The FAST project was designed to develop and test resources to assist families of youth and young adults with disabilities through the transition from school to adult life. Its curriculum development and training components focused specifically on people who were ethnically and socioeconomically diverse. This report describes a national survey developed in conjunction with the FAST project to increase our understanding of the key information needs, unmet service needs, and service quality for youth and young adults with disabilities in transition from school to adulthood (defined for this effort as ages 12 to 22 years).

RESEARCH QUESTIONS

What are the needs of parents nationally with regard to the transition of their children with disabilities from youth to adulthood? Do those needs differ for parents of youth with disabilities by age, disability type or household income?

- How important is it for families to get information about youth development, family support and leadership skills, career development and employment, and adult services?
- What proportion of families of transition age youth with disabilities report unmet needs for help regarding transition supports?
- What services do families of transition age youth who are connected to Parent Information Centers currently receive?
- How good are the services currently received by transition age youth and their families?
- How do families of children with disabilities get information about transition supports?

METHODOLOGY AND SAMPLE

Focus groups were conducted to inform the development of an online survey that examines the knowledge and access to resources families of youth with disabilities between the ages of 12-22 have or lack as they move through the transition from school to adult life.

GATHER INFORMATION ON AWARENESS OF AND CURRENT ACCESS TO FAMILY SUPPORT SERVICES, AND TO IDENTIFY UNMET FAMILY SUPPORT NEEDS.

FAST project staff developed focus group protocols with input from the Partnership Board and in consultation with the University of MN. In March 2010, FAST Partners in 6 states conducted 10 structured focus groups with 90 families of youth between the ages of 12-22 to gather information on awareness of current access to family support services, and to identify unmet

family support needs. Focus group participants were asked to discuss several topics under the categories of youth development, family support and leadership, career development and employment, and connecting activities. During discussion the facilitator noted whether or not the topic seemed to be very important, somewhat important, or not important and recorded where participants said they go to get information or help on the topic. The collected data was analyzed by the FAST project and the University of Minnesota and used to inform the development of the national online survey.

MULTICULTURAL FOCUS GROUP SUMMARY

A total of nine focus groups in New York and Minnesota were conducted with 54 parents in December 2009. The majority of parents interviewed had a son or daughter between the ages of 12-22. The parents, staff facilitators, and focus group recorders represented Somali, Hmong, and African American cultures, as well as the cultures of the Dominican Republic, Honduras, Puerto Rico, Mexico, and Ecuador. Seven of the eleven staff who facilitated/recorded the focus group discussions are parents of children with disabilities. Each focus group discussion was conducted in the speaker's native language. Facilitators were instructed to re-word questions if they felt they could elicit more of a response.

COMMUNICATION STRATEGIES

Parents expressed interest in a wide range of trainings but the following were most commonly mentioned: training on specific skills for behavior management, education on specific disabilities, sexual education, trainings geared to the entire family (siblings, fathers), stress management and communicating with their children. Some parents also stated they wanted more interactive trainings, not just lecture trainings, and said they would use DVDs, video, and even online training at the library which would allow them to revisit material as needed

Short, follow-up phone calls were mentioned most often as the best way to conduct a survey. Phone numbers and address were preferred contact information. Two groups stated that organizations come into their community to gather information to acquire grant money and never return. "Everyone is trying to get funds, but not everyone has their best interests in heart."

TOPICAL RESULTS

EMPLOYMENT

Parents' visions for their child's future varied from specifics (cook, beautician, working at McDonalds, computer engineer, mechanic) to the general hope that they would be able to live

independently and lead a happy life. Most of the parents were not familiar with any local or state postsecondary programs serving students with disabilities. Many of the parents believed that their child would continue to live with family members or close by family members, while some expressed the desire for their child to live independently. Most did not consider a group home or nursing facility an option.

- “Six parents stated they would not allow their children/young adults to move to group homes because of what they have heard from other families in the community. Some families had heard group homes were like apartments for their disabled children/young adults and so they put them in a group home only to lose any rights to be involved for support or decision making for their disabled young adult.”

SEXUALITY/PUBERTY

Parents of older children acknowledged that their children do show interest in the opposite sex, and some were aware of people with disabilities in relationships. Parents of some cultures commented that relationships would be likely to cause more problems and expressed worry that their children would not be able to form relationships. Many said they are dealing with other issues and do not think about this, but some had very specific concerns and were dealing with problems in school related to sexuality or were worried, for example, about a child’s desire to touch girls.

- “My son, who is 14, has started asking questions or mimicking other kids about sexuality and gender differences. I never thought I would be speaking to my kids about etiquettes or how to interact with opposite gender.”

Most of the groups with older children expressed interest in workshops on sexual education in general, how to communicate about it, how to deal with issues of sexual abuse, etc. One group said they receive enough information from physicians and their families and did not need any other information. Another group was not comfortable with the subject.

- “Even though they were answering the questions, I could clearly see by their reaction that they did not believe their children had good chance of having normal life. Also, paying attention to a child's personal growth is not part of the culture.”

ADVOCATING FOR YOUR FAMILY & STRATEGIES FOR SYSTEMS CHANGE

All participants said they had advocated for their child with an educator or professional. Parent’s comments reflected an overall negative viewpoint of involvement with the education system and professionals, with a majority saying they were ignored, put down, did not see results, were frustrated, or confused. One group of five parents said they were being listened

to. And one parent said she felt respected and received services after attending a meeting with an advocate.

- “I feel like I am struggling for my child’s rights, but I will do what I have to do.”
- “Some are helpful and they seem to be trying to help. But many times I feel educators or professionals (doctors) stereotype me. Their attitude is ‘we are the professionals; we know what is best for your child, so you need to listen to us.’ ”

Parents reported advocating for and making changes in services for their son or daughter with a disability. Some were satisfied, but others were not, and said they “would just move out of the area rather than try to fight against a system that would not listen to them anyway.” Some wanted changes but didn’t know what to do. One group said they had communicated with elected officials but things remained the same. Approximately eight others wrote or talked with local officials. The majority had not written or talked to a state legislator or elected officials.

INSTRUMENT DEVELOPMENT

Survey questions were developed based on outcomes of focus groups and with input from the Partnership Board and in consultation with the University of MN. A pilot of survey questions was conducted with 12 Parent Center staff of youth with disabilities to refine content wording and determine length.

SURVEY PROCESS

Once the survey protocols were complete and the University of Minnesota’s Human Subjects Committee had approved them, the FAST Partners and other national disability networks were contacted with a media packet that provided several ways they could use to inform parents of the availability of the national survey. The packet included a news release, website posting and link, newsletter insert, email format, and a PDF of the survey in both English and Spanish. The survey was disseminated in all 50 states and territories. Collaborating Parent Centers were asked to recruit at least 20 parents to respond from among those who had completed one or more training sessions. Surveys were available in electronic form on the FAST website, and were also available in print in English, Spanish and Chinese.

SAMPLE

RESPONDENTS

A total of 2,416 surveys were returned. Most (92%) were completed by a parent of a young person with disabilities (See Table 1). The respondent was a grandparent for 3% of the surveys;

another relative or guardian for 3%; and a surrogate or foster parent 2.2%. The remaining surveys were from people with some other relationship with the person with a disability.

More than half of the respondents (58%) had a household income of more than \$50,000 per year while 31% reported an annual income of \$20,000 to \$50,000, and the remaining 11% reporting an annual household income of less than \$20,000. Most respondents were married (75%), with the others evenly split between those who were never married and those who were formerly married or partnered.

Responses were received from people in 50 states, the District of Columbia, American Samoa, Canada, and Puerto Rico. The greatest number of responses were received from New York (n = 170), Oregon (n=145) and California (n=105). Twenty or more responses were received from 35 states.

PERSONS WITH DISABILITIES

The vast majority of respondents (93%) answered the survey about a family member with whom they shared a home (n=2,234). A few (4%) reported that their family member lived in a group home or foster home (n = 91) or independently (3%, n=61). Only 16 respondents reported that their family member lived on the campus of a college or postsecondary school, 7 reported their family member lived at a PreK-12 residential school, 3 reported their family member was in jail and 2 reported that the family member lived with a spouse or significant other.

Most respondents reported that their family member was white (81%). Of the others 8% reported their family member was black or African American, 3% reported their family member was Asian, 2% reported their family member was American Indian or Alaska Native, 1% reported their family member was a Pacific Islander, and 6% reported some other race, did not know , or chose not to answer the question. Ten percent of the respondents reported that their family member Spanish/Hispanic/Latino.

Respondents were asked to identify the primary disability of their family members (See Table 2). The most common primary disability for family members was Autism Spectrum Disorders (34%). Intellectual or developmental disabilities were the next largest primary diagnosis (14%). None of the other disabilities were mentioned by more than 7% of respondents. Many families selected two or more disability categories. Open ended responses were reclassified by project staff when it was possible to match a diagnosis to a specific label. After reviewing all the open ended responses, the family members were classified into one of three broad groups.

The Intellectual or Developmental Disability group included those with a primary diagnosis of Intellectual Disability or Multiple Disabilities and the majority (51%) of those who used the open ended space to list a condition not on the original survey.

Autism spectrum disorders included those reporting ASD as a primary diagnosis and 10% of those reporting an “other disability.”

The OTHER category included the remaining family members listed as having an “other disability” as well as those with any of the other listed disability types. The most common other disabilities were Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder (7% of the total sample), Emotional Disturbance or Mental Illness (6%), and Specific Learning Disability (4%). Fewer than 2% of the overall sample reported having an Orthopedic Impairment, Traumatic Brain Injury, Deaf or Hard of Hearing, Speech/Language Impairment, Blindness or Vision Impairment, or Developmental Delay (for children younger than 6 years). The eight respondents who responded “Don’t know/prefer not to say “were included in the OTHER category.

Overall 857 of the respondents (36%) reported the primary disability of their family member to be an Autism Spectrum Disorder, 849 (35%) reported the primary disability of their family member to be an Intellectual or Developmental Disability, and 710 (29%) identified their family member as having some other type of disability.

SURVEY RESULTS

CHARACTERISTICS OF FAMILY MEMBERS BY DISABILITY CATEGORY

The characteristics of family members with disabilities (FMD) were compared for those with Autism Spectrum Disorder (ASD), Intellectual or Developmental Disabilities (IDD), and all others (OTHER, See Table 3). Overall, the mean age of FMD was 15.5 years, with FMD with IDD being statistically significantly older (16.3 years on average) than those with ASD or in the OTHER group.

Overall, 93% of FMD were living with a parent or other family member. Individuals with ASD or IDD were significantly more likely to be living with a family member (93% and 95% respectively) than those in the OTHER category (See Table 3)¹.

¹ Because this survey was completed by some but not all U.S. respondents whose family member had a disability, statistical tests were used to determine how likely it would be to find a difference of this size solely by chance. We used three different cut off points to describe the likelihood that a difference of this size was due to who we included in the sample. On the tables it is recorded as follows: p < .05 is noted by *; p<.01 is noted as **; p < .001 is noted as ***. * means that we would find a difference of this size 95 of 100 times we picked different families to be in the survey (we would draw the wrong conclusion 5% of the time). ** means we would find a difference of this size 99 of 100 times (drawing the wrong conclusion 1% of the time); *** means we would find this difference 999 of 1000 times (we would draw the wrong conclusion 0.1% of the time). When we compared three groups (for example when we compared respondents in the IDD group, the ASD group and the OTHER group), we also did another statistical test to see which of the groups was different from which other group.

Overall, 64% of family members with disabilities were male. Individuals with ASD were more likely to be male (79%) than either of the other groups. Individuals with an OTHER diagnosis were more likely to be male (63%) than those with IDD (50%). Overall, 73% of individuals with disabilities were white and non-Hispanic. FMD with an OTHER diagnosis were significantly less likely to be white and non-Hispanic (64%) than the other two groups (77% for IDD, and 76% for ASD). The vast majority of FMD were reported to speak English as their first language, with more FMD in the ASD group speaking English than in the IDD or OTHER group.

As one of the main foci of this project was to examine underrepresented groups, zip codes reported by respondents were matched to U.S. Census Bureau files to identify the percent of families in the zip code with annual household incomes below the federal poverty rate, and the median family income for households in the zip code. These two items refer to the community in which the respondent lived, not necessarily to the respondents themselves. Overall in the communities in which respondents lived 7% of all families had annual household incomes of less than the federal poverty rate. Respondents with FMD in the OTHER category lived in communities where the proportion of families living below the poverty level was significantly higher (8%) than the communities in which FMD in the IDD or ASD categories lived. The median family income in the communities in which respondents lived was \$57,595. Respondents whose family member had an OTHER disability lived in communities with significantly lower median incomes than respondents whose family member had IDD or ASD.

This project examined the characteristics and needs of respondents who had a member with a disability in the transition age period. Overall, 11% of respondents had family members ages 11 or younger, 47% had family members between 12 and 16 years, 40% had family members ages 17 to 22 years, and 2% had family members ages 23 to 39 years. Respondents whose family member had IDD provided information about an older family member than respondents whose family member had ASD or an OTHER disability. Specifically, 17 to 22 years were the most prevalent ages for families with a member with IDD while 12 to 16 years were the most common age group for families with a member with ASD or OTHER.

INFORMATION NEEDS, SUPPORT QUALITY AND UNMET NEEDS OF FAMILY MEMBERS

INFORMATION NEEDS

Respondents evaluated how important it was for them to receive information about preparing their family member for adult living in five categories: Youth Development, Family Support and Leadership, Career Development and Employment, Adult Services, and Education. The question was "How important is it for you to know how to get supports for" each topic. Response choices included "Very Important", "Somewhat Important", or "Not Important" (See Table 4). The response categories were converted to numeric values with "Very Important" getting a 2, "Somewhat important" a 1 and "Not important" a 0. Table 4 shows the mean importance of knowing how to get supports in each category and compares relative importance of each item by disability group (IDD,ASD,OTHER), and for two of the age categories (12 to 16 years, and 17

to 22 years). Respondents with family members younger than 12 or older than 22 were not included in the age group analyses.

OVERALL IMPORTANCE OF INFORMATION

Respondents rated the importance of knowing how to get information about 22 different topics. With two exceptions (Finding a support group for your son or daughter, and Finding a support group for yourself), at least 50% of all families rated the information as “very important”. The five information needs rated as most important overall (and the percentage reporting it was very important) were:

1. Helping your son or daughter improve social skills and build lifelong friendships (85%)
2. Advocating for your son or daughter’s rights (85%)
3. Helping your son or daughter develop skills for living on their own (85%)
4. Obtaining medical care and health insurance for your son or daughter (85%)
5. Helping your son or daughter be prepared to work (85%)

Neither of the items in the Education category was among the top five overall.

IMPORTANCE BY DISABILITY CATEGORY

The most important information needed by respondents varied by disability group. For respondents whose family member had IDD, the most important information needs were:

1. Helping your son or daughter find and participate in recreation, hobbies and other activities or interests
2. Helping your son or daughter improve social skills and build lifelong friendships
3. Advocating for your son or daughter’s rights
4. Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/herself
5. Obtaining medical care and health insurance for your son or daughter

In each of these categories respondents whose family member had IDD rated getting information as significantly more important than respondents whose family member had an OTHER disability type did. For one item (“Helping your son or daughter find and participate in recreation, hobbies and other activities or interests”), respondents whose family member had IDD rated getting information as significantly more important than respondents whose family member had ASD.

For respondents whose family member had ASD, the most important information needs were:

1. Helping your son or daughter develop skills for living on their own
2. Helping your son or daughter improve social skills and build lifelong friendships
3. Helping your son or daughter find and keep a job
4. Advocating for your son or daughter’s rights

5. Obtaining medical care and health insurance for your son or daughter

Respondents whose family member had ASD rated all of these items as more important than respondents whose family member had an OTHER disability, and two of the items “Helping your son or daughter develop skills for living on their own,” and “Helping your son or daughter find and keep a job” as more important than respondents whose family member had an IDD.

For respondents whose family member had an OTHER disability, the most important information needs were:

1. Helping your son or daughter be prepared to work
2. Finding and choosing vocational education, job training and employment programs for your son or daughter
3. Helping your son or daughter develop skills for living on their own
4. Helping your son or daughter succeed at school and prepare for post-secondary education
5. Finding and choosing postsecondary education options for your son or daughter

Respondents whose family member had an OTHER disability rated each of these five items as more important than respondents whose family member had IDD. They rated the items on Vocational Education and Post-Secondary Education as more important than respondents whose family members had either IDD or ASD.

None of the five items rated as most important overall were mentioned by respondents in all three groups. Respondents with family members in the IDD or ASD groups but not the OTHER disability group rated obtaining medical care as one of their most important needs.

Respondents with family members in the ASD and OTHER groups the IDD group rated helping your family member develop skills for living on their own one of their most important information needs.

IMPORTANCE BY AGE GROUP

Respondents identified different information needs as most important depending on whether their family member was 12 to 16 years old or 17 to 22 years old. Respondents whose family member was 12 to 16 years old rated 13 of the 22 items as more important than respondents whose family member was 17 to 21 years old (See Table 4).

The highest ranked items rated more important for respondents of the younger group included:

- Helping your son or daughter improve social skills and build lifelong friendships
- Advocating for your son or daughter’s rights
- Helping your son or daughter develop skills for living on their own
- Finding and choosing vocational education, job training and employment programs for your son or daughter

- Helping your son or daughter find and participate in recreation, hobbies and other activities or interests

Both groups rated these items as very important but respondents whose family member was 12 to 16 years old rated these items as more important than respondents whose family member was 17 to 22 years old.

The highest ranked items rated as equally as important by respondents in both age groups included:

- Obtaining medical care and health insurance for your son or daughter
- Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself
- Finding and choosing vocational education, job training and employment programs for your son or daughter
- Helping your son or daughter find and participate in recreation, hobbies and other activities or interests
- Helping your son or daughter with housing and support services

UNMET NEEDS OF FAMILIES AND INDIVIDUALS WITH DISABILITIES

The next set of questions asked respondents about support needs they had that were not being met. Respondents with unmet needs were compared to respondents who said they did not need help and respondents who were currently receiving the support. The number of respondents reporting an unmet need in each category ranged from 250 (for "Advocating for your son or daughter's rights") to 678 (for "Preparing your son or daughter for healthy, loving adult relationships.")

UNMET NEEDS FOR ALL RESPONDENTS

The proportion of respondents needing but not receiving supports ranged from 19% for "advocating for your son or daughter's rights" to 41% for "Helping your son or daughter with housing and support services". On average across the 22 items 31% of respondents reported needing but not receiving supports.

More than a third of respondents reported needing but not receiving supports in the following areas:

- Helping your son or daughter with housing and support services (41%)
- Preparing others to fulfill your role in the future (39%)
- Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself (39%)
- Finding a support group for your son or daughter (38%)

- Providing transportation for your son or daughter (38%)
- Helping your son or daughter find and keep a job (37%)
- Preparing your son or daughter for healthy, loving adult relationships (36%)
- Helping your son or daughter be prepared to work (34%)
- Finding and choosing vocational education, job training and employment programs for your son or daughter (33%)

Of the other supports, 3 were identified as unmet by 30 to 33% of the respondents, 8 were identified as unmet needs by 25% to 29% of the respondents and 3 were identified as unmet by 19% to 24% of the respondents.

UNMET NEEDS BY DISABILITY CATEGORY

Fewer than 35% of respondents whose family member had IDD reported unmet needs in any of the listed areas. The most frequently identified unmet needs for this group were:

- Providing transportation for your son or daughter (35%)
- Helping your son or daughter with housing and support services (33%)
- Finding a support group for your son or daughter (32%)
- Preparing others to fulfill your role in the future (32%)
- Helping your son or daughter find and keep a job (31%)

Significantly fewer respondents whose family member had IDD reported unmet needs for the listed supports than did respondents in one or both of the other categories. In each of the 17 areas where the groups differed, significantly fewer respondents whose family member had IDD reported an unmet need than respondents whose family member had ASD. For 9 of these areas fewer respondents of family members with IDD reported fewer unmet needs than respondents whose family member had an OTHER disability.

For 11 of the support areas, more than 35% of respondents whose family member had ASD reported unmet needs. More than 40% of those families reported unmet needs for the following supports:

- Preparing others to fulfill your role in the future (48%)
- Helping your son or daughter with housing and support services (48%)
- Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself (45%)
- Providing transportation for your son or daughter (44%)
- Preparing your son or daughter for healthy, loving adult relationships (44%)
- Helping your son or daughter find and keep a job (43%)
- Finding a support group for your son or daughter (42%)
- Helping your son or daughter be prepared to work (40%)

Respondents whose family member had ASD reported significantly more unmet needs than respondents whose family member had IDD for 17 items. They reported significantly more unmet needs than respondents whose family member had an OTHER disability for two items "Preparing your son or daughter for healthy, loving adult relationships" and "Providing transportation for your son or daughter".

More than 35% of respondents whose family member had an OTHER disability identified unmet needs in the following areas:

- Helping your son or daughter with housing and support services (43%)
- Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself (42%)
- Finding a support group for your son or daughter (39%)
- Helping your son or daughter find and keep a job (38%)
- Preparing others to fulfill your role in the future (36%)
- Helping your son or daughter be prepared to work (35%)
- Providing transportation for your son or daughter (35%)

Respondents whose family member had an OTHER disability were more likely than respondents whose family member had IDD on to have unmet needs in nine support areas.

While there were distinct differences between the three disability groups, the groups shared five of six most frequently mentioned unmet needs:

- Preparing others to fulfill your role in the future
- Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself
- Providing transportation for your son or daughter
- Finding a support group for your son or daughter
- Helping your son or daughter find and keep a job

Only one of the six items "Helping your son or daughter with housing and support services" was identified differently by the three groups (with respondents in the IDD group less likely than those in the ASD and OTHER groups to identify this as a current unmet need).

UNMET NEEDS BY AGE GROUP

Respondents whose family member was 12 to 16 years old were significantly more likely to report unmet needs than respondents whose family member was 17 to 22 years old for 14 of the 22 supports. The most common unmet needs for respondents whose family member was 12 to 16 years old were:

- Helping your son or daughter with housing and support services (50%)
- Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself (48%)
- Helping your son or daughter find and keep a job (45%)
- Providing transportation for your son or daughter (44%)
- Preparing others to fulfill your role in the future (44%)

The most common unmet needs for respondents whose family member was 17 to 22 years old were:

- Preparing your son or daughter for healthy, loving adult relationships (36%)
- Finding a support group for your son or daughter (35%)
- Preparing others to fulfill your role in the future (32%)
- Helping your son or daughter with housing and support services (31%)
- Providing transportation for your son or daughter (31%)

The most frequently mentioned unmet needs for each age group overlapped for only two of the six most commonly mentioned unmet needs "Preparing others to fulfill your role in the future" and "Providing transportation for your son or daughters."

UNMET NEEDS FOR FAMILIES WITH DIFFERING ANNUAL HOUSEHOLD INCOMES

Respondents reported their annual household income in three categories "less than \$20,000", "\$20,000 to \$50,000" and "more than \$50,000".

More than 40% of respondents reporting annual household incomes of less than \$20,000 reported unmet needs in 10 areas:

- Finding a support group for your son or daughter (45%)
- How your role as a parent legally changes when your son or daughter turns 18 (guardianship, conservatorship, power of attorney) (42%)
- Preparing others to fulfill your role in the future (41%)
- Finding support group for yourself (42%)
- Finding and choosing vocational education, job training and employment programs for your son or daughter (43%)
- Helping your son or daughter be prepared to work (42%)
- Helping your son or daughter find and keep a job (46%)
- Helping your son or daughter with housing and support services (47%)
- Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself (42%)
- Providing transportation for your son or daughter (40%)

More than 40% of respondents with annual incomes of \$20,000 to \$50,000 reported unmet needs in these areas:

- Finding a support group for your son or daughter (40%)
- Preparing others to fulfill your role in the future (43%)
- Helping your son or daughter find and keep a job (40%)
- Helping your son or daughter with housing and support services (45%)
- Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself (41%)
- Providing transportation for your son or daughter (40%)

The proportion of respondents with annual incomes of more than \$50,000 reporting unmet needs did not exceed 40% for any categories. The most frequently identified unmet needs for this group were:

- Preparing your son or daughter for healthy, loving adult relationships (38%)
- Helping your son or daughter with housing and support services (38%)
- Providing transportation for your son or daughter (38%)
- Preparing others to fulfill your role in the future (37%)
- Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself (37%)
- Finding a support group for your son or daughter (36%)
- Helping your son or daughter find and keep a job (35%)

The proportion of respondents reporting unmet needs differed significantly for 10 of the 22 items. In every case, respondents with a lower annual household income levels were significantly more likely to report having unmet needs than those with higher income levels. For three of those items families in the lowest income group reported unmet needs more often than those in the highest income group but not those in the middle income category. Those items were:

- Helping your son or daughter develop skills for living on their own (38%)
- Finding a support group for your son or daughter (45%)
- Success stories from other parents or adults with the same disabilities as your son or daughter (35%)

They reported unmet needs more often than both of the other groups on the remaining seven items.

Of the six most commonly reported unmet needs overall, only two were among the most frequently mentioned unmet needs for all three groups:

- Helping your son or daughter with housing and support services

- Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself

SUPPORTS NEEDED BY RESPONDENTS

Respondents had three choices with regard to how to answer questions about transition related supports. They could indicate that they needed the listed support but were not receiving it (discussed in the previous section), that they did not need the listed support (discussed in this section), or that they received the listed support (discussed in the next section).

The number of respondents reporting they did not need a listed support ranged from 282 (12%) for "Helping your son or daughter find and participate in recreation, hobbies, and other activities or interests" to 683 (13%) for "Helping your son or daughter find and keep a job." The three least frequently needed supports were needed by 74% of all respondents. Those supports included:

- Obtaining personal care, child care, respite services, in-home health care supports for your son or daughter
- Finding support group for yourself
- Obtaining mental health services for your son or daughter

The proportion of respondents reporting they needed the remaining 18 supports ranged from 76% to 90%.

The most commonly needed supports across all groups were:

- Finding and choosing vocational education, job training and employment programs for your son or daughter (90%)
- Advocating for your son or daughter's rights (90%)
- Helping your son or daughter be prepared to work (89%)
- Helping your son or daughter find and participate in recreation, hobbies, and other activities or interests (88%)
- Helping your son or daughter find and keep a job (87%)

QUALITY OF SUPPORTS RECEIVED BY RESPONDENTS

Respondents who indicated that they currently received any of 22 listed supports rated the quality of those supports as: Excellent (4), Good (3), "fair" (2), or Poor (1). The number of respondents who rated the supports ranged from 977 (for "Housing and support services") to 1,561 (for "Advocating for your son or daughter's rights.") An average of 1,219 respondents evaluated the quality of each listed support (See Table 6). As in the previous section we will

describe the overall average rating by respondents and then examine differences in the quality of supports by disability group, age, and household income.

OVERALL

Average ratings of quality could range from 1 (poor) to 4 (excellent). The overall average quality rating across the 22 items was 2.19 (fair). Looking at the item closest to this average can help explain what these numbers mean. A total of 1,124 respondents rated the quality of supports they received for the item "Finding and choosing postsecondary education options for your son or daughter." Overall, 97 respondents said the supports they received in this area were excellent, 230 reported their supports were good, 367 reported the supports were "fair", and 430 said the supports were poor. The average of 2.19 for this item suggests that on whole families reported the quality of supports for finding and choosing postsecondary options were "fair". Put another way, 29% of the respondents rated supports for finding and choosing post secondary education options as good or excellent.

The quality ratings for supports ranged from 2.0 to 2.5 except for one item rated as 2.59 and two items below 2.0 (one was 1.94, the other 1.99). Scores between 1.5 and 2.5 were in the "fair" quality range. Supports rated by respondents as having the highest quality were:

- Advocating for your son or daughter's rights (2.59, good)
- How your role as a parent legally changes when your son or daughter turns 18 (guardianship, conservatorship, power of attorney) (2.42, fair)
- Helping your son or daughter develop skills for self-care, hygiene, and safety (2.38, fair)
- Finding support group for yourself (2.35, fair)
- Obtaining medical care and health insurance for your son or daughter (2.35, fair)

The ranking for the top item about advocacy should be interpreted in the context of this survey. Respondents who had recently completed training provided by the parent centers were the primary target respondents.

Current support ranked lowest in quality (all in the "fair" category) included:

- Finding and choosing vocational education, job training and employment programs for your son or daughter (2.05)
- Helping your son or daughter be prepared to work (2.05)
- Preparing your son or daughter for healthy, loving adult relationships (2.04)
- Preparing others to fulfill your role in the future (2.03)
- Finding a support group for your son or daughter (2.02)
- Finding and choosing postsecondary education options for your son or daughter (1.99)
- Helping your son or daughter find and keep a job (1.94)

DIFFERENCES BY DISABILITY GROUP

There were statistically significant differences between respondents in the three disability groups for eight items reported. Respondents whose family member had an OTHER disability rated the quality of the following four supports more positively than those in either the IDD or ASD groups:

- Helping your son or daughter develop skills for self-care, hygiene, and safety
- Preparing your son or daughter for healthy, loving adult relationships
- Obtaining mental health services for your son or daughter
- Finding and choosing postsecondary education options for your son or daughter

With regard to helping the family member develop self-care, hygiene and safety skills respondents of those in the OTHER group rated their supports as "good" while the other groups rated them as "fair". For the other three items all groups rated the supports as "fair" but respondents whose family member was in the OTHER group reported receiving slightly higher quality supports.

Respondents with family members with IDD reported receiving significantly higher quality supports for the following items:

- How your role as a parent legally changes when your son or daughter turns 18 (guardianship, conservatorship, power of attorney)
- Advocating for your son or daughter's rights
- Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself
- Obtaining medical care and health insurance for your son or daughter

In the cases of legal changes and advocacy, respondents whose family member had IDD reported receiving "good" quality supports while family members of the OTHER group rated them as "fair". On the other two items all groups rated the quality of supports as "fair" but respondents whose family member had IDD reported receiving slightly higher quality supports than those by respondents whose family member had ASD.

DIFFERENCES BY AGE GROUP

The quality of three supports was significantly different for the younger and older groups. In all three cases respondents whose family member was 11 to 16 years old reported receiving higher quality supports than respondents whose family members were 17 to 22 years old. Those items were:

- Helping your son or daughter find and participate in recreation, hobbies, and other activities or interests
- Preparing your son or daughter for healthy, loving adult relationships

- Providing transportation for your son or daughter

It may be that respondents with younger family members were still benefitting from school related supports while respondents with older family members were no longer receiving the same type of supports regarding activities and relationships. Differences on transportation could also reflect differences between school based and community based transportation options.

DIFFERENCES BY HOUSEHOLD INCOME

Income related differences in reported support quality were noted for 10 of the 22 supports. In each case, respondents with annual household incomes of less than \$20,000 per year reported that the quality of the supports they received was higher than one or both of the higher income groups. However, in nine of the ten cases the groups all rated quality as "fair. For one item, "Obtaining medical care and health insurance for your son or daughter" respondents with the lowest incomes reported supports were "good" while those in the other income groups reported supports of "fair" quality. This difference may reflect differences in access to public health care for people with the lowest income levels.

Respondents living in communities where a higher proportion of residents earned less than the federal poverty rate in 2000 were slightly more likely to report higher quality of supports than those in communities where fewer households earned less than the federal poverty rate. The strongest correlations were reported for the supports on which respondents with incomes below \$20,000 per year reported receiving higher quality supports.

RESOURCES FOR INFORMATION

The next section of the survey asked respondents to identify resources they used to find information about supports for family members as they move toward adulthood. Results are reported as the simple percentage of respondents who said used each type of information.

OVERALL

Each of the 26 listed information sources was identified as being used to find information by at least some respondents. The most widely used resources and the percentage of respondents reporting they used them were:

- Advocacy organization (63%)
- Teacher, social worker, counselor, or other school staff (57%)
- Books, magazines, TV, radio (55%)
- Friend/family member (52%)

- Internet (49%)
- Support groups or another parent (47%)
- Workshops and/or conferences (46%)
- Disability organization (41%)
- County or regional welfare or social services agency, social worker or case manager (37%)

DIFFERENCES BY DISABILITY GROUP

The resources used by respondents to find information about supports differed for the three disability groups. Information sources used by 50% or more of the respondents whose family member had IDD were:

- Advocacy organization
- Teacher, social worker, counselor, or other school staff
- Friend/family member
- Disability organization
- Support groups or another parent

Information sources used by 50% or more of the respondents whose family members had ASD were:

- Advocacy organization
- Books, magazines, TV, radio
- Teacher, social worker, counselor, or other school staff
- Internet
- Friend/family member
- Support groups or another parent

Information sources used by 50% or more of the respondents whose family members had an OTHER disability included:

- Advocacy organization
- Teacher, social worker, counselor, or other school staff
- Books, magazines, TV, radio
- Friend/family member

Of the five resources used most often overall, three were among the top five resources for all three disability groups.

- Advocacy organization
- Teacher, social worker, counselor, or other school staff
- Friend/family member

Respondents in all three disability groups reported similar rates of usage for the following nine resources:

- Teacher, social worker, counselor, or other school staff (used by 57% of all respondents)
- Friend/family member (52%)
- Community organization or center (29%)
- Public health nurse, nurse, doctor or other medical provider (27%)
- Parent Center (26%)
- Self-advocacy group for people with disabilities (22%)
- Vocational Rehabilitation Service (17%)
- Centers for Independent Living (14%)
- Other (6%)

Resources used more often by respondents whose family member had IDD more often than the respondents in one or both of the other groups are listed here in order from most to least frequently used by respondents in the IDD group. Resources used also more often by respondents in the ASD group than respondents in the OTHER group have a * next to them.

- Disability organization*
- Support groups or another parent*
- Workshops and/or conferences*
- County or regional welfare or social services agency, social worker or case manager*
- Recreation program, Special Olympics*
- Service provider agency
- State Developmental Disabilities, Ombudsman's, Department of Human Services or Department of Health Office*
- Developmental Disability Council
- Protection and Advocacy Office (Law)

Most of these resources are disability specific or disability focused.

Respondents in the ASD group were most likely than one or both of the other groups to report using: advocacy organizations; books, magazines, TV and radio; and the internet.

Respondents in the OTHER disability group were more likely than one or both of the other groups to report using:

- College or University
- Library (also used more frequently by respondents in the ASD group than in the IDD group)
- Religious organization
- Cultural center or organization

With the exception of use of advocacy organizations by respondents in the ASD group, all of the information sources used disproportionately by respondents in the ASD and/or OTHER groups were generic community resources rather than disability specific resources.

DIFFERENCES BY AGE GROUP

Four of the five most frequently used sources were used by similar proportions of respondents in both the older and younger age categories:

- Advocacy organization
- Teacher, social worker, counselor, or other school staff
- Books, magazines, TV, radio
- Friend/family member

Respondents whose family member was 17 to 22 years old were more likely than respondents whose family members were younger to use the following information sources:

- Workshops and/or conferences
- Disability organization
- County or regional welfare or social services agency, social worker or case manager
- Service provider agency
- Community organization or center
- Vocational Rehabilitation Service
- State Developmental Disabilities, Ombudsman's, Department of Human Services or Department of Health Office
- Recreation program, Special Olympics
- College or University
- Developmental Disability Council
- Centers for Independent Living
- Protection and Advocacy Office (Law)

None of the resources were used significantly more often by respondents of the younger group.

DIFFERENCES BY HOUSEHOLD INCOME

Nine information sources were accessed differently by respondents with different levels of household income. Families with the highest incomes were more likely to use support groups, workshops and disability organizations than families in the other groups.

Respondents in the top and middle income categories were more likely than respondents with annual household incomes below \$20,000 to use advocacy groups or colleges or universities as resources.

Respondents with annual household incomes of \$20,000 to \$50,000 were more likely than those with higher or lower household incomes to seek information from the Vocational Rehabilitation Service program.

Finally respondents with annual household incomes of less than \$20,000 were more likely to seek information from public health or other medical providers and libraries. They were also more likely to report that they either had not sought information from any of these sources, or that they did not know where to find information about supports for family members who were becoming adults.

CURRENT SUPPORTS RECEIVED BY THE FAMILY MEMBER WITH A DISABILITY

The final question asked respondents to report whether their family member currently received any of a list of services. The proportion of respondents reporting their family member received the support is listed.

OVERALL

Overall, the most commonly used services were K-12 schools (67%), health insurance (48%), case management (42%), Medicaid (41%), Behavioral or mental health services (35%), and specialist services or therapies (31%).

DIFFERENCES BY DISABILITY GROUP

Respondents whose family members had IDD were more likely than either of the other respondent groups to be using the following 12 services:

- Medicaid
- Case management or service coordination
- Health insurance coverage
- Specialist services such as occupational, physical or speech therapy
- Respite care/family support
- Supports at home (such as a home health aide, or personal care attendant)
- Adaptive aids or equipment
- Assistive technology (e.g., augmentative communication device)
- Environmental modifications (including modifications to the person's home or vehicle)
- Specialized transportation services
- Non-vocational day program for adults
- Homemaker/chore services

Respondents whose family members had IDD or ASD were more likely than those in the OTHER category to report using K-12 school services.

Respondents whose family member had ASD or an OTHER disability were more likely than those in the IDD group to report using behavioral or mental health services.

Respondents whose family member had an OTHER disability were more likely than the other groups to receive Post-secondary education services, or none of the listed supports.

There were statistically significant differences between respondents in the three disability groups for all of the five most used current supports.

DIFFERENCES BY AGE GROUP

Age related differences in service use were noted for 13 of the 21 listed services. Services used more often by family members ages 12 to 16 years included:

- School (Kindergarten through grade 12)
- Specialist services such as occupational, physical or speech therapy
- Behavioral or mental health services
- Parent training and education

Services used more often by family members ages 17 to 22 years included:

- Medicaid
- Case management or service coordination
- Supports at home (such as a home health aide, or personal care attendant)
- Specialized transportation services
- School (Technical, vocational, community college, college, university)
- Non-vocational day program for adults
- Job coach, employment or vocational rehabilitation services
- Supports to help my family member live in his/her own home (such as budgeting help, shopping, or meal planning)
- Homemaker/chore services

DIFFERENCES BY HOUSEHOLD INCOME

For 13 of the listed services, no income related differences were reported.

Respondents with household incomes of \$50,000 or less were more likely to use Medicaid than those with incomes greater than \$50,000.

Families with incomes between \$20,000 and \$50,000 were more likely than those with incomes of less than \$20,000 to use case management or service coordination services.

Respondents with annual household incomes of less than \$20,000 were more likely than the other groups to use another unspecified service type, supports to help the family member live in his or her own home, and homemaker or chore services.

Respondents with annual household incomes of more than \$50,000 were more like than families with less income to use health insurance coverage, post-secondary education, and environmental modifications.

DISCUSSION

Responses to the national FAST survey revealed a complex pattern of differences between respondents whose family members were in different disability categories, age groups, or household income categories. These groups differed in their ratings of the importance of information on various topics, the extent to which family members needed but were not receiving transition related support, the reported quality of transition related supports received, the most commonly used sources of information about services for individuals with disabilities approaching adulthood, and the current use of various generic and disability specific supports.

CRITICAL CHALLENGES FOR YOUTH WITH DISABILITIES AND THEIR FAMILY MEMBERS IN THE TRANSITION AGE GROUP

Many sections in this report identify challenges or unmet needs for transition age youth with disabilities. Among the most pressing is the substantial amount of unmet transition to adulthood related support needs reported by respondents (See Table 5). Another pressing issue is the low ratings of the quality of transition supports currently used by families (See Table 6). Improving the transition outcomes for youth and young adults with disabilities will require attention to both of these issues.

Only the respondents of youth with OTHER disabilities reported getting information about post-secondary information as a top priority. This suggests that there is a general lack of awareness amongst families of youth with ASD and IDD about the post-secondary options that might be available to those family members.

Policymakers and funding organizations must recognize that the scope of unmet needs reported by families of youth with disabilities calls for transition-focused parent training not only related to the Individuals with Disabilities Education Act (IDEA), but to more substantive information on employment issues, post-secondary education options, transportation strategies, housing and independent living, health care, social skill development, and government support programs for adults with disabilities.

IMPLICATIONS FOR PARENT CENTERS AND OTHER GROUPS SUPPORTING TRANSITION AGE YOUTH AND YOUNG ADULTS WITH DISABILITIES

These results hold several implications for Parent Centers and other groups supporting transition age youth and young adults with disabilities.

Providing transition related information and services are not “one-size fits all” tasks. Parent centers, advocacy organizations, schools and other groups whose mission includes supporting youth and young adults with disabilities and their families through the transition period will need to be strategic about how they can best meet the need of the disability group(s), age group(s), and income levels of the youth and families they seek to help.

When it is not practical to differentiate the approaches used to assist youth and young adults with different disabilities, of different ages, or in different socioeconomic statuses, organizations will be most effective if they prioritize their efforts to reach groups they are best suited to serve. In some cases this will mean building or strengthening partnerships with organizations with similar goals but for different populations, ages or socioeconomic statuses.

On the other hand, there are some topics, resources, and supports that are common across disability types, ages and socioeconomic statuses. For those topics, resources and supports, organizations seeking to serve this population would be well advised to consider joint efforts to reduce duplicative activities.

Social skills and friendships were rated as important information needs overall and in IDD/ASD categories; and preparing son/daughter for healthy relationships was rated highly as an unmet need. To effectively meet those informational needs Parent Centers may have to change their practices. They can use the curricula developed for this project to begin to address this need. However, more information and support is likely needed. Parent Centers that tend to focus more on employment or education issues will either need to expand their focus to include this topic, or to connect with other organizations including University Centers of Excellence, Developmental Disability Councils, and other advocacy groups to fill in the gaps.

Family members in ASD category had high unmet needs in preparing other to fill their role, housing, financial support, etc. With relatively recent increase in diagnosis of autism, and as that group ages, these results suggest that there may be a need to target trainings/information to families of children with autism about adult services and long term supports.

Families of children with disabilities in younger age group reported more unmet needs. This finding re-affirms need to start transition planning early.

UNEXPECTED OPPORTUNITIES EMERGING FROM THIS PROJECT

While we did not try to control the type of disabilities of the youth and young adults about who the survey asked, we ended up with a sample well distributed on three dimensions: age, type of disability, and socioeconomic status. This allowed us to not only describe results for youth and young adults in general but also to look at key differences on those three dimensions. As it turns out, the questions asked in the study had different answers from respondents on all three of those dimensions. Respondents were also diverse with respect to race and ethnicity.

STUDY LIMITATIONS

While this study included families from throughout the United States and its Territories, the number of families responding from some states was much smaller than others and is not necessarily proportional to the number of transition age youth with disabilities in those locales.

While this study began with a very specific sample frame (families who participated in training on one or more of four topics offered by Parent Centers throughout the United States), in the end many respondents reported not using Parent Centers as an information source for this type of information. While this adds diversity to the sample, it also makes it more difficult to accurately define the population from which the respondents were drawn. The survey was posted to the internet and links were created to this information by many Parent Centers. In some states, other groups such as advocacy organizations, schools, and various State Agencies also disseminated information about the survey. The good thing about that is the sample size was very large (2,416) even though the survey was fielded for only a short period of time.

Overall, 27% of the respondents ($N = 646$) were from one or more underrepresented group (i.e., they reported incomes of less than \$20,000, race or ethnicity other than White Non-Hispanic, a language other than English is the parents first language). This is a relatively large number of people from underrepresented groups. The surveys were available on paper and in Spanish and Chinese versions, and Parent Center staff in many of the states offered to assist families to complete the survey if they needed it. However, since the survey was primarily offered in an on-line version, the respondents may be different than others who are in underrepresented groups.

FAST

PACER's National Family Advocacy and Support Training Project

2010 FAST Family Support Survey National Results Final

3/15/2011

ICI @ U of MN

Report prepared for the FAST project of PACER Center
by the
University of Minnesota, Research and Training Center on Community Living



Table 1: Characteristics of Respondents and Persons with Disabilities		
Respondent Characteristics	N	Percent
Role		
Parent of a young person with disabilities	2,416	92%
Grandparent of a young person with disabilities	2,416	3%
Other relative/guardian of a young person with disabilities	2,416	3%
Surrogate/Foster parent of a young person with disabilities	2,416	2%
Other	2,416	5%
Household income		
Less than \$20,000 per year	215	11%
\$20,000 to \$50,000 per year	581	31%
More than \$50,000 per year	1,085	58%
Marital status		
Married/Partnered	1,472	75%
Single	257	13%
Formerly married/partnered	229	12%
Characteristics of Persons with Disabilities		
Living Arrangement (recoded)		
With parents or other family members	2,234	93%
In a group home, foster home or other residence	91	4%
Independently/ In his her own home or apartment	61	3%
College or postsecondary school	16	1%
Residential school (Pre-K-12)	7	0%
Jail	3	0%
With spouse/significant other	2	0%
Race		
White	1,626	81%
Black or African American	162	8%
Other race not listed	89	4%
Asian (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese or Other Asian)	68	3%
American Indian or Alaska Native	48	2%
Don't know/prefer not to say	46	2%
Pacific Islander (Native Hawaiian, Guamanian or Chamorro, Samoan, or Other Pacific Islander)	24	1%
Ethnicity		
Not Spanish/Hispanic/Latino	1,574	85%
Spanish/Hispanic/Latino (Mexican, Mexican American, Chicano, Puerto Rican, Cuban or other)	170	9%
Don't know/prefer not to say	102	6%

National responses by State			
State	N	State	N
AK	15	ND	31
AL	11	NE	23
AR	29	NH	39
AS	15	NJ	21
AZ	85	NM	27
CA	105	NV	27
Canada	1	NY	170
CO	32	OH	66
CT	38	OK	11
DC	2	OR	145
DE	26	PA	54
FL	86	PR	13
GA	28	RI	15
HI	6	SC	10
IA	4	SD	29
ID	13	TN	71
IL	59	TX	57
IN	20	UT	64
KS	50	VA	46
KY	22	VI	7
LA	58	VT	19
MA	42	WA	18
MD	71	WI	40
ME	8	WV	1
MI	57	WY	3
MN	63		
MO	19		
MS	22		
NC	45		

Table 2 Disability type and Category for family members of respondents

Characteristics of person with a disability	N	Percent	Disability Category		
			IDD	ASD	Other
Autism Spectrum Disorders (Autism or Asperger's) (ASD)	821	34.0%	0	821	0
Other disability	347	14.4%	177	36	134
Multiple Disabilities	334	13.8%	334	0	0
Intellectual Disability (developmental cognitive disabilities or Down Syndrome) (IDD)	332	13.7%	332	0	0
Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder	180	7.5%	0	3	177
Emotional Disturbance or Mental Illness	138	5.7%	0	1	137
Specific Learning Disability	98	4.1%	0	0	98
Orthopedic Impairment	38	1.6%	0	0	38
Traumatic Brain Injury	34	1.4%	0	0	34
Deaf or Hard of Hearing	28	1.2%	0	0	28
Speech/Language impairment	27	1.1%	0	0	27
Blindness or Vision Impairment	17	0.7%	0	0	17
Developmental Delay (children younger than 6 years)	14	0.6%	6	0	8
Don't know/prefer not to say	8	0.3%	0	0	8

Disability Category	N	Percent
Autism Spectrum Disorders	857	36%
Intellectual or developmental disability	849	35%
Other	710	29%

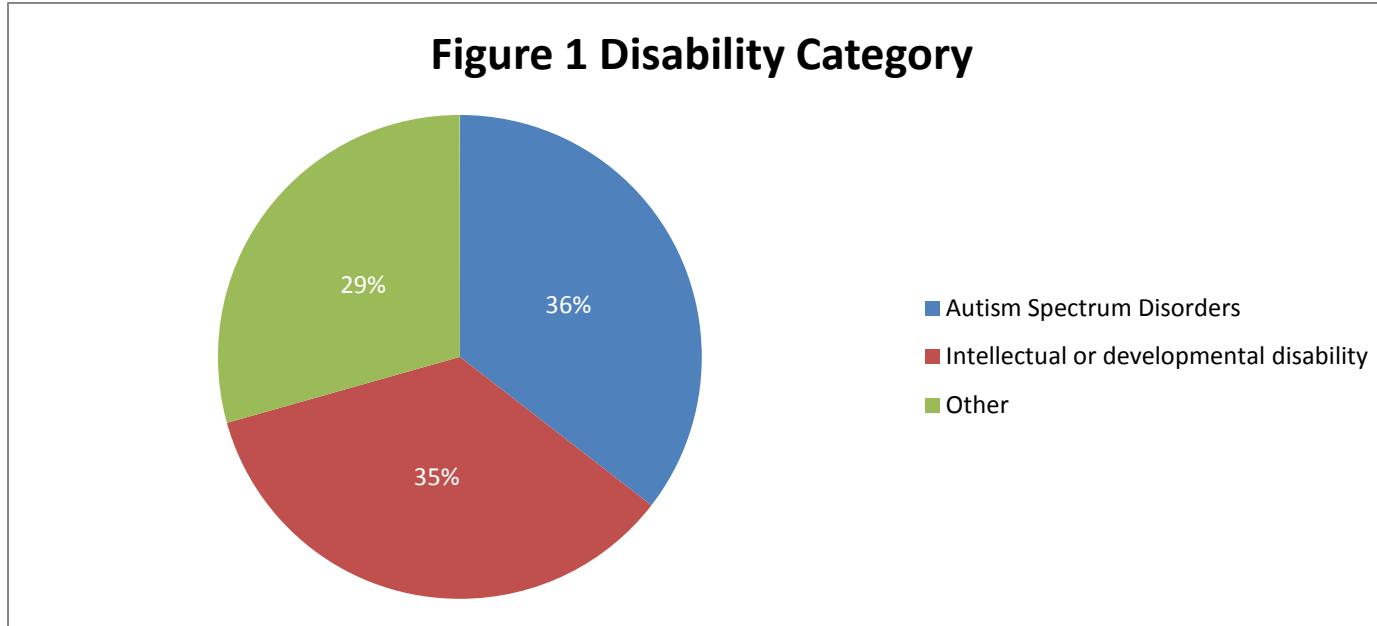
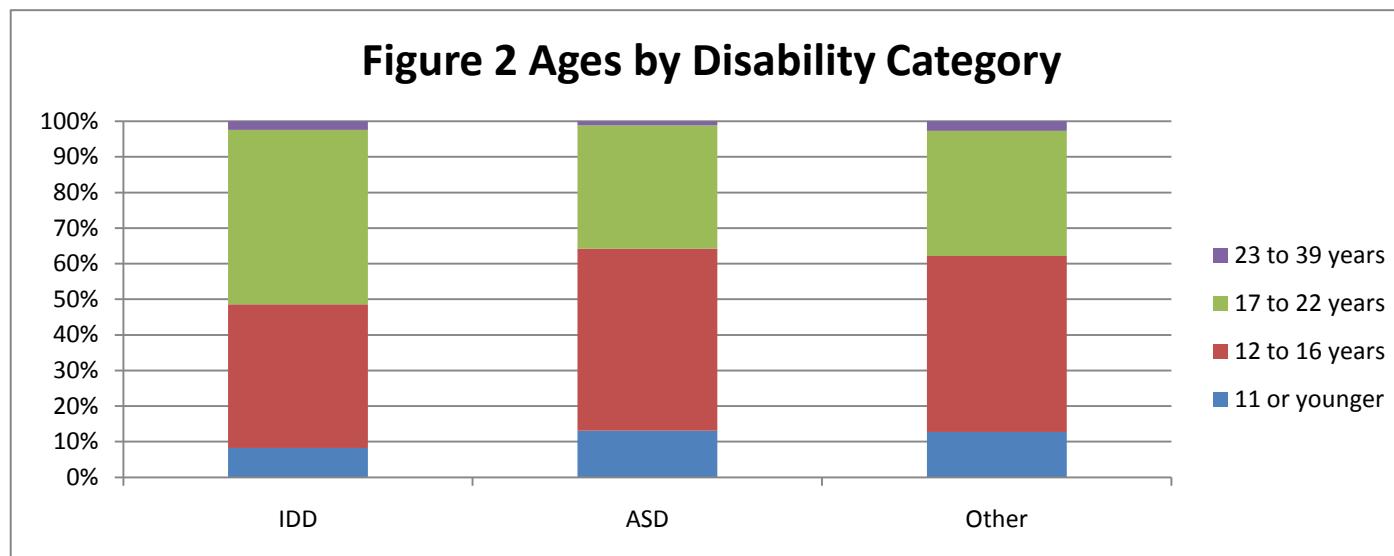


Table 3 Additional Characteristics of family members with a disability and differences by disability category

Additional Demographics	N	Mean/ Percent	Disability Category			F	Sig.	Mean Differences
			IDD	ASD	Other			
Characteristics of person with a disability								
Mean Age	2,363	15.5	16.3 93% 50% 77% 96%	15.0	15.4	20.18	***	IDD > ASD, Other
Lives with parent or family member	2,234	93%		95%	89%	8.21	***	IDD, ASD > Other
Gender is Male	2,006	64%		79%	63%	67.07	***	ASD > Other > IDD
White Non-Hispanic	1,796	73%		76%	64%	15.13	***	IDD,ASD > Other
English is Primary Language Understood	1,907	96%		98%	95%	6.14	**	ASD > IDD,Other
Community Characteristics by Zipcode								
Percent of Families below the poverty level	1,782	7%	7% \$58,361	7%	8%	6.90	**	Other > IDD,ASD
Median Family Income	1,790	\$57,595		\$58,755	\$55,075	5.21	**	IDD,ASD > Other

Age Category	N	Percent	Disability Category			Chi-Square
			IDD	ASD	Other	
11 or younger	266	11%	8% 40% 49% 2%	13%	13%	54.97***
12 to 16 years	1,108	47%		51%	50%	
17 to 22 years	940	40%		35%	35%	
23 to 39 years	49	2%		1%	3%	



How important is it for you to know how to get supports for:								
	Very Important		Somewhat Important		Not Important		N	Average Score
	N	%	N	%	N	%		
B. Youth Development (Preparing for adult living)								
Helping your son or daughter improve social skills and build lifelong friendships	1,987	87%	234	10%	58	3%	2,279	1.85
Helping your son or daughter develop skills for living on their own	1,941	85%	235	10%	103	5%	2,279	1.81
Helping your son or daughter find and participate in recreation, hobbies and other activities or interests	1,817	80%	390	17%	72	3%	2,279	1.77
Helping your son or daughter develop skills for self-care, hygiene and safety	1,837	81%	272	12%	170	7%	2,279	1.73
Preparing your son or daughter for healthy, loving adult relationships	1,723	76%	405	18%	149	7%	2,277	1.69
Finding a support group for your son or daughter	1,086	48%	837	37%	356	16%	2,279	1.32
C. Family Support and Leadership Skills								
Advocating for your son or daughter's rights	1,833	85%	290	13%	46	2%	2,169	1.82
How your role as a parent legally changes when your son or daughter turns 18 (guardianship, conservatorship, power of attorney)	1,670	77%	315	15%	184	8%	2,169	1.69
Preparing others to fulfill your role in the future	1,507	69%	446	21%	216	10%	2,169	1.60
Success stories from other parents or adults with the same disabilities as your son or daughter	1,263	58%	734	34%	172	8%	2,169	1.50
Obtaining personal care, child care, respite services, in-home health care supports for your son or daughter	1,222	56%	381	18%	566	26%	2,169	1.30
Finding a support group for yourself	792	37%	811	37%	566	26%	2,169	1.10
D. Career Development and Employment (Preparing for Work)								
Helping your son or daughter be prepared to work	1,806	85%	196	9%	129	6%	2,131	1.79
Finding and choosing vocational education, job training and employment programs for your son or daughter	1,796	84%	209	10%	126	6%	2,131	1.78
Helping your son or daughter find and keep a job	1,763	83%	219	10%	149	7%	2,131	1.76
E. Adult Services (Finding services as an adult)								
Obtaining medical care and health insurance for your son or daughter	1,780	85%	205	10%	105	5%	2,090	1.80
Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself	1,726	83%	223	11%	141	7%	2,090	1.76
Helping your son or daughter with housing and support services	1,577	75%	347	17%	166	8%	2,090	1.68
Providing transportation for your son or daughter	1,456	70%	387	19%	126	6%	2,089	1.58
Obtaining mental health services for your son or daughter	1,349	65%	395	19%	346	17%	2,090	1.48
F. Education (Success at School, Choosing Post-Secondary Options)								
Helping your son or daughter succeed at school and prepare for post-secondary education	1,534	74%	252	12%	296	14%	2,082	1.59
Finding and choosing postsecondary education options for your son or daughter	1,448	70%	291	14%	343	16%	2,082	1.53

Group most likely to say this is important

An average score of 0 to 0.5 indicates people thought the item was not important.

An average score of 0.51 to 1.5 indicates people thought the item was somewhat important.

An average score of 1.51 to 2.0 indicates people thought the item was very important.

Table 4. Importance of knowing how to get supports for the transition to adulthood by disability group and age group

How important is it for you to know how to get supports for:	Disability Group					
	IDD	ASD	Other	F	Sig	Comparisons
B. Youth Development (Preparing for adult living)						
Helping your son or daughter improve social skills and build lifelong friendships	1.84	1.90	1.79	11.10	***	ASD > IDD > Other
Helping your son or daughter develop skills for living on their own	1.69	1.90	1.84	41.06	***	ASD > Other > IDD
Helping your son or daughter find and participate in recreation, hobbies and other activities or interests	1.85	1.78	1.65	32.00	***	IDD>ASD>Other
Helping your son or daughter develop skills for self-care, hygiene and safety	1.78	1.83	1.56	43.70	***	IDD,ASD>Other
Preparing your son or daughter for healthy, loving adult relationships	1.77	1.74	1.58	23.57	***	Other,ASD>IDD
Finding a support group for your son or daughter	1.29	1.39	1.27	5.87	**	ASD>IDD,Other
C. Family Support and Leadership Skills						
Advocating for your son or daughter's rights	1.83	1.85	1.78	6.16	**	IDD,ASD>Other
How your role as a parent legally changes when your son or daughter turns 18 (guardianship, conservatorship, power of attorney)	1.78	1.76	1.47	52.87	***	IDD,ASD>Other
Preparing others to fulfill your role in the future	1.75	1.70	1.30	115.69	***	IDD,ASD>Other
Success stories from other parents or adults with the same disabilities as your son or daughter	1.48	1.50	1.53	0.56		
Obtaining personal care, child care, respite services, in-home health care supports for your son or daughter	1.57	1.33	0.96	108.33	***	IDD>ASD>Other
Finding a support group for yourself	1.08	1.13	1.11	0.52		
D. Career Development and Employment (Preparing for Work)						
Helping your son or daughter be prepared to work	1.66	1.81	1.89	41.02	***	ASD > Other > IDD
Finding and choosing vocational education, job training and employment programs for your son or daughter	1.71	1.76	1.87	18.97	***	Other>IDD,ASD
Helping your son or daughter find and keep a job	1.62	1.86	1.79	37.73	***	ASD > Other > IDD
E. Adult Services (Finding services as an adult)						
Obtaining medical care and health insurance for your son or daughter	1.83	1.85	1.72	13.73	***	IDD,ASD>Other
Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself	1.83	1.83	1.59	44.87	***	IDD,ASD>Other
Helping your son or daughter with housing and support services	1.74	1.77	1.48	46.28	***	IDD,ASD>Other
Providing transportation for your son or daughter	1.72	1.66	1.31	76.31	***	IDD,ASD>Other
Obtaining mental health services for your son or daughter	1.27	1.66	1.50	52.27	***	ASD > Other > IDD
F. Education (Success at School, Choosing Post-Secondary Options)						
Helping your son or daughter succeed at school and prepare for post-secondary education	1.35	1.64	1.82	80.36	***	Other>ADD>IDD
Finding and choosing postsecondary education options for your son or daughter	1.25	1.57	1.80	94.86	***	Other>ADD>IDD

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

Group most likely to say this is important

An average score of 0 to 0.5 for indicates people thought the item was not important.

An average score of 0.51 to 1.5 indicates people thought the item was somewhat important.

An average score of 1.51 to 2.0 indicates people thought the item was very important.

Table 4. Importance of knowing how to get supports for the transition to adulthood by disability group and age group

How important is it for you to know how to get supports for:	Age Group			
	12 to 16	17 to 22	F	Sig
B. Youth Development (Preparing for adult living)				
Helping your son or daughter improve social skills and build lifelong friendships	1.86	1.82	3.89	*
Helping your son or daughter develop skills for living on their own	1.84	1.77	11.52	**
Helping your son or daughter find and participate in recreation, hobbies and other activities or interests	1.76	1.77	0.04	
Helping your son or daughter develop skills for self-care, hygiene and safety	1.76	1.68	7.44	**
Preparing your son or daughter for healthy, loving adult relationships	1.73	1.64	10.38	**
Finding a support group for your son or daughter	1.36	1.25	11.06	**
C. Family Support and Leadership Skills				
Advocating for your son or daughter's rights	1.85	1.78	11.70	**
How your role as a parent <u>legally</u> changes when your son or daughter turns 18 (guardianship, conservatorship, power of attorney)	1.73	1.66	5.69	*
Preparing others to fulfill your role in the future	1.58	1.62	2.39	
Success stories from other parents or adults with the same disabilities as your son or daughter	1.56	1.44	17.01	***
Obtaining personal care, child care, respite services, in-home health care supports for your son or daughter	1.26	1.30	1.00	
Finding a support group for yourself	1.14	1.02	11.44	**
D. Career Development and Employment (Preparing for Work)				
Helping your son or daughter be prepared to work	1.83	1.75	11.23	**
Finding and choosing vocational education, job training and employment programs for your son or daughter	1.81	1.77	2.81	
Helping your son or daughter find and keep a job	1.79	1.73	5.39	*
E. Adult Services (Finding services as an adult)				
Obtaining medical care and health insurance for your son or daughter	1.79	1.81	0.33	
Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself	1.74	1.78	2.77	
Helping your son or daughter with housing and support services	1.66	1.69	1.38	
Providing transportation for your son or daughter	1.56	1.60	1.29	
Obtaining mental health services for your son or daughter	1.49	1.43	2.26	
F. Education (Success at School, Choosing Post-Secondary Options)				
Helping your son or daughter succeed at school and prepare for post-secondary education	1.69	1.44	54.56	***
Finding and choosing postsecondary education options for your son or daughter	1.63	1.38	48.14	***

Group most likely to say this is important

An average score of 0 to 0.5 indicates people thought the item was not important.

An average score of 0.51 to 1.5 indicates people thought the item was somewhat important.

An average score of 1.51 to 2.0 indicates people thought the item was very important.

Table 5 Unmet needs of families of transition age youth with disabilities

	Total	Disability Group					
		a	b	c	F	Sig	Comparisons
		IDD	ASD	Other			
Proportion of Families who need help but are not currently receiving help (Excluding those who do not need help)							
B. Youth Development (Preparing for adult living)							
Finding a support group for your son or daughter	38%	32%	42%	39%	7.00	***	IDD < ASD, OTHER
Preparing your son or daughter for healthy, loving adult relationships	36%	30%	44%	34%	14.77	***	IDD, OTHER < ASD
Helping your son or daughter develop skills for living on their own	29%	23%	35%	29%	13.05	***	IDD < ASD, OTHER
Helping your son or daughter improve social skills and build lifelong friendships	27%	23%	29%	27%	2.91		
Helping your son or daughter find and participate in recreation, hobbies, and other activities or interests	26%	21%	29%	28%	6.37	**	IDD < ASD, OTHER
Helping your son or daughter develop skills for self-care, hygiene, and safety	23%	19%	27%	23%	5.82	**	IDD < ASD
C. Family Support and Leadership Skills							
Preparing others to fulfill your role in the future	39%	32%	48%	36%	19.07	***	IDD < ASD
Finding support group for yourself	30%	28%	30%	32%	1.18		
How your role as a parent <u>legally</u> changes when your son or daughter turns 18 (guardianship, conservatorship, power of attorney)	29%	22%	35%	29%	13.72	***	IDD < ASD, OTHER
Success stories from other parents or adults with the same disabilities as your son or daughter	27%	24%	28%	29%	3.01	*	ns
Obtaining personal care, child care, respite services, in-home health care supports for your son or daughter	26%	22%	31%	26%	6.19	**	IDD < ASD
Advocating for your son or daughter's rights	19%	16%	21%	19%	3.69	*	IDD < ASD
D. Career Development and Employment (Preparing for Work)							
Helping your son or daughter find and keep a job	37%	31%	43%	38%	11.33	***	IDD < ASD, OTHER
Helping your son or daughter be prepared to work	34%	26%	40%	35%	13.28	***	IDD < ASD, OTHER
Finding and choosing vocational education, job training and employment programs for your son or daughter	33%	28%	37%	34%	6.44	**	IDD < ASD
E. Adult Services (Finding services as an adult)							
Helping your son or daughter with housing and support services	41%	33%	48%	43%	14.83	***	IDD < ASD, OTHER
Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself	39%	30%	45%	42%	16.52	***	IDD < ASD, OTHER
Providing transportation for your son or daughter	38%	34%	44%	35%	7.31	***	IDD, OTHER < ASD
Obtaining mental health services for your son or daughter	31%	26%	34%	32%	4.42	*	IDD < ASD
Obtaining medical care and health insurance for your son or daughter	28%	21%	32%	31%	11.74	***	IDD < ASD, OTHER
F. Education (Success at School, Choosing Post-Secondary Options)							
Finding and choosing postsecondary education options for your son or daughter	32%	30%	34%	32%	1.03		
Helping your son or daughter succeed at school and prepare for post-secondary education	23%	23%	24%	24%	0.11		

Groups more likely to report an unmet need

Across all unmet needs, with disability group, age and income as predictors only age of the individual was a statistically significant overall predictor of unmet need with families of younger children reporting more unmet need.

Items with greater than 1/3 of respondents saying they have an unmet need are highlighted in green

Table 5 Unmet needs of families of transition age youth with disabilities

	Age Group			
	12 to 16	17 to 22	F	Sig
Proportion of Families who need help but are not currently receiving help (Excluding those who do not need help)				
B. Youth Development (Preparing for adult living)				
Finding a support group for your son or daughter	39%	35%	3.23	
Preparing your son or daughter for healthy, loving adult relationships	37%	36%	.20	
Helping your son or daughter develop skills for living on their own	32%	27%	5.11 *	
Helping your son or daughter improve social skills and build lifelong friendships	26%	28%	.98	
Helping your son or daughter find and participate in recreation, hobbies, and other activities or interests	27%	25%	.49	
Helping your son or daughter develop skills for self-care, hygiene, and safety	25%	20%	6.51 *	
C. Family Support and Leadership Skills				
Preparing others to fulfill your role in the future	44%	32%	21.84 ***	
Finding support group for yourself				
How your role as a parent <u>legally</u> changes when your son or daughter turns 18 (guardianship, conservatorship, power of attorney)	36%	18%	70.32 ***	
Success stories from other parents or adults with the same disabilities as your son or daughter	28%	25%	1.74	
Obtaining personal care, child care, respite services, in-home health care supports for your son or daughter	30%	21%	12.13 **	
Advocating for your son or daughter's rights	20%	16%	4.16 *	
D. Career Development and Employment (Preparing for Work)				
Helping your son or daughter find and keep a job	45%	28%	56.40 ***	
Helping your son or daughter be prepared to work	41%	23%	64.37 ***	
Finding and choosing vocational education, job training and employment programs for your son or daughter	42%	21%	91.49 ***	
E. Adult Services (Finding services as an adult)				
Helping your son or daughter with housing and support services	50%	31%	55.07 ***	
Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself	48%	29%	60.94 ***	
Providing transportation for your son or daughter	44%	31%	25.62 ***	
Obtaining mental health services for your son or daughter	37%	22%	34.75 ***	
Obtaining medical care and health insurance for your son or daughter	34%	21%	30.59 ***	
F. Education (Success at School, Choosing Post-Secondary Options)				
Finding and choosing postsecondary education options for your son or daughter	38%	24%	34.85 ***	
Helping your son or daughter succeed at school and prepare for post-secondary education	27%	18%	16.56 ***	

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

Across all unmet needs, with disability group, age and income as predictors only age of the individual was a statistically significant overall predictor of unmet need with families of younger children reporting more unmet need.

Items with greater than 1/3 of respondents saying they have an unmet need are highlighted in green

Table 5 Unmet needs of families of transition age youth with disabilities

Proportion of Families who need help but are not currently receiving help (Excluding those who do not need help)	Household Income(in \$,000s)								
	a	b	c	LT \$20	\$20 to \$50	MT \$50	F	Sig	Comparisons
B. Youth Development (Preparing for adult living)									
Finding a support group for your son or daughter	45%	40%	36%	3.06	*	c < a			
Preparing your son or daughter for healthy, loving adult relationships	39%	37%	38%	0.17					
Helping your son or daughter develop skills for living on their own	38%	33%	27%	5.50	**	c < a			
Helping your son or daughter improve social skills and build lifelong friendships	31%	30%	25%	3.03	*	ns			
Helping your son or daughter find and participate in recreation, hobbies, and other activities or interests	31%	28%	24%	2.52					
Helping your son or daughter develop skills for self-care, hygiene, and safety	29%	26%	21%	3.27	*	ns			
C. Family Support and Leadership Skills									
Preparing others to fulfill your role in the future	41%	43%	37%	2.30					
Finding support group for yourself									
How your role as a parent <u>legally</u> changes when your son or daughter turns 18 (guardianship, conservatorship, power of attorney)	42%	32%	27%	8.60	***	c < a,b			
Success stories from other parents or adults with the same disabilities as your son or daughter	35%	29%	25%	5.00	**	c < a			
Obtaining personal care, child care, respite services, in-home health care supports for your son or daughter	33%	28%	25%	2.32					
Advocating for your son or daughter's rights	25%	23%	16%	7.92	***	c < a,b			
D. Career Development and Employment (Preparing for Work)									
Helping your son or daughter find and keep a job	46%	40%	35%	4.20	*	c < a,b			
Helping your son or daughter be prepared to work	42%	38%	31%	6.03	**	c < a,b			
Finding and choosing vocational education, job training and employment programs for your son or daughter	43%	36%	31%	5.87	**	c < a,b			
E. Adult Services (Finding services as an adult)									
Helping your son or daughter with housing and support services	47%	45%	38%	4.38	*	ns			
Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself	42%	41%	37%	1.64					
Providing transportation for your son or daughter	40%	40%	38%	0.55					
Obtaining mental health services for your son or daughter	33%	33%	30%	0.60					
Obtaining medical care and health insurance for your son or daughter	29%	28%	29%	0.07					
F. Education (Success at School, Choosing Post-Secondary Options)									
Finding and choosing postsecondary education options for your son or daughter	38%	36%	29%	4.83	**	ns			
Helping your son or daughter succeed at school and prepare for post-secondary education	30%	26%	21%	5.43	**	c < a,b			

Groups more likely to report an unmet need

Across all unmet needs, with disability group, age and income as predictors only age of the individual was a statistically significant overall predictor of unmet need with families of younger children reporting more unmet need.

Items with greater than 1/3 of respondents saying they have an unmet need are highlighted in green

Quality of Supports Received (For those who reported getting supports)	Disability Group							
	Overall		Disability Group					
	N	Mean	a	b	c	F	Sig	Comparisons
B. Youth Development (Preparing for adult living)								
Helping your son or daughter develop skills for self-care, hygiene, and safety	1,313	2.38	2.38	2.29	2.50	5.45	**	Other > IDD, ASD
Helping your son or daughter develop skills for living on their own	1,369	2.30	2.31	2.27	2.33	0.60		
Helping your son or daughter find and participate in recreation, hobbies, and other activities or interests	1,481	2.27	2.32	2.19	2.31	3.16	*	
Helping your son or daughter improve social skills and build lifelong friendships	1,538	2.23	2.25	2.19	2.25	0.89		
Preparing your son or daughter for healthy, loving adult relationships	1,201	2.04	1.99	1.95	2.19	8.25	***	Other > IDD, ASD
Finding a support group for your son or daughter	1,073	2.02	2.02	2.00	2.06	0.36		
C. Family Support and Leadership Skills								
Advocating for your son or daughter's rights	1,561	2.59	2.68	2.58	2.51	3.87	*	IDD>Other
How your role as a parent <u>legally</u> changes when your son or daughter turns 18 (guardianship, conservatorship, power of attorney)	1,295	2.42	2.53	2.43	2.23	9.55	***	IDD, ASD > Other
Finding support group for yourself	1,080	2.35	2.34	2.36	2.34	0.06		
Success stories from other parents or adults with the same disabilities as your son or daughter	1,329	2.31	2.33	2.28	2.34	0.68		
Obtaining personal care, child care, respite services, in-home health care supports for your son or daughter	1,132	2.23	2.31	2.15	2.19	3.38	*	
Preparing others to fulfill your role in the future	1,078	2.03	2.03	2.00	2.05	0.27		
D. Career Development and Employment (Preparing for Work)								
Finding and choosing vocational education, job training and employment programs for your son or daughter	1,257	2.05	2.08	1.99	2.08	1.40		
Helping your son or daughter be prepared to work	1,244	2.05	2.09	1.99	2.06	1.48		
Helping your son or daughter find and keep a job	1,139	1.94	1.96	1.89	1.99	1.28		
E. Adult Services (Finding services as an adult)								
Obtaining medical care and health insurance for your son or daughter	1,233	2.35	2.45	2.23	2.34	6.33	*	IDD>ASD
Obtaining mental health services for your son or daughter	1,014	2.16	2.15	2.08	2.30	4.16	*	Other > IDD, ASD
Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself	1,072	2.08	2.18	2.00	2.03	4.58	*	IDD>ASD, Other
Providing transportation for your son or daughter	980	2.06	2.11	2.15	1.94	4.31	*	
Helping your son or daughter with housing and support services	977	2.04	2.11	1.96	2.03	2.56		
F. Education (Success at School, Choosing Post-Secondary Options)								
Helping your son or daughter succeed at school and prepare for post-secondary education	1,323	2.17	2.17	2.13	2.22	0.88		
Finding and choosing postsecondary education options for your son or daughter	1,124	1.99	1.94	1.94	2.11	3.71	*	Other > IDD, ASD

Groups rating the quality of current supports the highest
 An average score between 1.0 and 1.5 indicates people thought the service was of poor quality.
 An average score between 1.51 and 2.5 indicates people thought the service was of fair quality.
 An average score between 2.51 and 3.5 indicates people thought the service was of good quality.
 An average score between 3.51 and 4.0 indicates people thought the service was of excellent quality.

Quality of Supports Received (For those who reported getting supports)		Age Group												Household Income(in \$1,000s)				Correlations	
		a		b		F		Sig		a	b	c	LT \$20	\$20 to \$50	MT \$50	F	Sig	Comparisons	
		12 to 16	17 to 22							LT \$20	\$20 to \$50	MT \$50					Zip '00 Poverty	Sig	
B. Youth Development (Preparing for adult living)	Helping your son or daughter develop skills for self-care, hygiene, and safety	2.38	2.36	0.19		2.55		2.35		2.39		2.51					0.07	*	
	Helping your son or daughter develop skills for living on their own	2.30	2.28	0.25		2.50		2.29		2.30		2.86					0.01		
	Helping your son or daughter find and participate in recreation, hobbies, and other activities or interests	2.31	2.19	5.54	*	2.55		2.35		2.39		0.38					0.06		
	Helping your son or daughter improve social skills and build lifelong friendships	2.24	2.19	1.08		2.31		2.24		2.21		3.03	*	c < a			0.05		
	Preparing your son or daughter for healthy, loving adult relationships	2.08	1.91	9.17	**	2.33		1.98		2.01		6.96	**	b,c < a			0.10	**	
	Finding a support group for your son or daughter	2.07	1.95	3.79		2.21		1.96		2.01		3.10	*	b < a			0.08	*	
C. Family Support and Leadership Skills	Advocating for your son or daughter's rights	2.64	2.56	2.47		2.68		2.68		2.59		1.48					0.07	**	
	How your role as a parent <u>legally</u> changes when your son or daughter turns 18 (guardianship, conservatorship, power of attorney)	2.39	2.49	2.86		2.42		2.38		2.48		1.21					0.02		
	Finding support group for yourself	2.38	2.33	0.46		2.39		2.28		2.40		1.46					0.05		
	Success stories from other parents or adults with the same disabilities as your son or daughter	2.36	2.27	2.70		2.48		2.38		2.29		2.75					0.10	**	
	Obtaining personal care, child care, respite services, in-home health care supports for your son or daughter	2.25	2.23	0.09		2.44		2.29		2.18		4.27	*	c < a			0.12	***	
	Preparing others to fulfill your role in the future	2.03	2.01	0.09		2.30		2.00		2.02		4.72	**	b,c < a			0.13	***	
D. Career Development and Employment (Preparing for Work)	Finding and choosing vocational education, job training and employment programs for your son or daughter	2.02	2.06	0.46		2.21		2.04		2.04		1.53					(0.01)		
	Helping your son or daughter be prepared to work	2.02	2.05	0.28		2.32		2.01		2.04		4.85	**	b,c < a			0.01		
	Helping your son or daughter find and keep a job	1.96	1.89	1.44		2.26		1.93		1.90		6.35	**	c < a			0.01		
E. Adult Services (Finding services as an adult)	Obtaining medical care and health insurance for your son or daughter	2.37	2.34	0.27		2.55		2.37		2.30		4.03	*	c < a			0.11	***	
	Obtaining mental health services for your son or daughter	2.23	2.11	3.64		2.42		2.15		2.11		5.18	**	c < a			0.13	**	
	Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself	2.08	2.10	0.14		2.20		2.08		2.07		1.01					0.06		
	Providing transportation for your son or daughter	2.12	1.97	5.81	*	2.40		2.02		2.00		8.10	***	c < a			0.14	**	
	Helping your son or daughter with housing and support services	2.09	1.98	3.07		2.20		2.03		2.01		1.76					0.12	**	
F. Education (Success at School, Choosing Post-Secondary Options)	Helping your son or daughter succeed at school and prepare for post-secondary education	2.18	2.14	0.50		2.19		2.11		2.20		0.96					-		
	Finding and choosing postsecondary education options for your son or daughter	2.01	1.96	0.71		2.17		1.96		1.96		2.22					0.01		

Groups rating the quality of current supports the highest

An average score between 1.0 and 1.5 indicates people thought the service was of poor quality.

An average score between 1.51 and 2.5 indicates people thought the service was of fair quality.

An average score between 2.51 and 3.5 indicates people thought the service was of good quality.

An average score between 3.51 and 4.0 indicates people thought the services was of excellent quality.

Table 7 Sources of information about supports

	% Yes	Disability Group					
		a IDD	b ASD	c Other	F	Sig	Comparisons
Which of these resources have you used to find information about supports for your family member as he or she moves towards adulthood?							
Advocacy organization	63%	63%	67%	60%	3.41	*	c<b
Teacher, social worker, counselor, or other school staff	57%	60%	57%	54%	2.11		
Books, magazines, TV, radio	55%	49%	63%	53%	16.88	***	a,c < b
Friend/family member	52%	55%	52%	50%	1.61		
Internet	49%	46%	53%	48%	3.85	*	a < b
Support groups or another parent	47%	49%	50%	41%	6.22	**	c < a, b
Workshops and/or conferences	46%	48%	48%	41%	4.23	*	c < a,b
Disability organization	41%	50%	41%	31%	25.43	***	c < b < a
County or regional welfare or social services agency, social worker or case manager	37%	46%	34%	29%	24.70	***	c < b < a
Community organization or center	29%	29%	32%	26%	2.95		
Public health nurse, nurse, doctor or other medical provider	27%	27%	26%	29%	0.93		
Service provider agency	27%	32%	26%	22%	7.89	***	b,c < a
Parent Center	26%	26%	26%	26%	0.02		
Recreation program, Special Olympics	25%	36%	25%	13%	45.44	***	c < b < a
State Developmental Disabilities, Ombudsman's, Department of Human Services or Department of Health Office	24%	28%	27%	16%	16.92	***	c < a,b
Self-advocacy group for people with disabilities	22%	24%	23%	19%	2.25		
College or University	20%	15%	21%	27%	15.64	***	a < b < c
Library	19%	14%	23%	20%	10.23	***	a < b,c
Developmental Disability Council	19%	24%	20%	12%	16.13	***	c < a,b
Vocational Rehabilitation Service	17%	18%	17%	17%	0.11		
Religious organization	16%	16%	13%	19%	4.91	**	b < c
Protection and Advocacy Office (Law)	15%	18%	12%	16%	4.56	*	b < a
Centers for Independent Living	14%	16%	14%	12%	2.58		
Cultural center or organization	3%	3%	2%	5%	3.22	*	a,b<c
Other	6%	7%	6%	6%	0.58		
None/I don't Know	3%	3%	2%	3%	1.15		

n = 2082; *** p < .001, ** p < .01, * p < .05

Groups that are more likely to use the source

Items endorsed by more than 1/3 of respondents are shown in green

Note: When interpreting this table remember that respondents may not classify organizations as advocacy, support groups, disability organizations, community organizations, or parent centers in the same way that you do.

Table 7 Sources of information about supports

Which of these resources have you used to find information about supports for your family member as he or she moves towards adulthood?	Age Group			
	a	b	F	Sig
	12 to 16	17 to 22		
Advocacy organization	63%	65%	0.56	
Teacher, social worker, counselor, or other school staff	57%	59%	0.68	
Books, magazines, TV, radio	57%	53%	2.04	
Friend/family member	51%	54%	1.21	
Internet	50%	48%	0.63	
Support groups or another parent	47%	47%	0.14	
Workshops and/or conferences	43%	51%	12.30	***
Disability organization	39%	45%	8.62	**
County or regional welfare or social services agency, social worker or case manager	31%	44%	34.54	***
Community organization or center	26%	31%	5.38	*
Public health nurse, nurse, doctor or other medical provider	28%	26%	1.63	
Service provider agency	23%	33%	22.90	***
Parent Center	26%	26%	0.01	
Recreation program, Special Olympics	24%	28%	4.25	*
State Developmental Disabilities, Ombudsman's, Department of Human Services or Department of Health Office	20%	30%	23.59	***
Self-advocacy group for people with disabilities	20%	24%	3.79	
College or University	15%	28%	43.11	***
Library	21%	18%	2.83	
Developmental Disability Council	17%	21%	6.66	**
Vocational Rehabilitation Service	7%	31%	205.11	***
Religious organization	15%	16%	0.05	
Protection and Advocacy Office (Law)	13%	17%	6.73	**
Centers for Independent Living	11%	18%	18.66	***
Cultural center or organization	3%	3%	0.17	
Other	6%	6%	0.10	
None/I don't Know	3%	2%	4.26	*

n = 2082; *** p < .001, ** p < .01, * p < .05

Groups that are more likely to use the source

Items endorsed by more than 1/3 of respondents are shown in green

Note: When interpreting this table remember that respondents may not classify organizations as advocacy, support groups, disability organizations, community organizations, or parent centers in the same way that you do.

Table 7 Sources of information about supports

Which of these resources have you used to find information about supports for your family member as he or she moves towards adulthood?	Household Income(in \$1,000s)				
	a	b	c	F	Sig
	LT \$20	\$20 to \$50	MT \$50		Comparisons
Advocacy organization	53%	61%	68%	9.39	***
Teacher, social worker, counselor, or other school staff	53%	55%	61%	3.68	*
Books, magazines, TV, radio	55%	53%	59%	2.97	
Friend/family member	50%	51%	54%	1.37	
Internet	43%	50%	51%	2.19	
Support groups or another parent	38%	44%	51%	8.11	***
Workshops and/or conferences	35%	43%	51%	10.67	***
Disability organization	33%	37%	46%	10.19	***
County or regional welfare or social services agency, social worker or case manager	40%	41%	35%	3.10	*
Community organization or center	31%	29%	29%	0.21	
Public health nurse, nurse, doctor or other medical provider	33%	30%	26%	3.26	*
Service provider agency	28%	29%	27%	0.48	
Parent Center	26%	30%	24%	2.83	
Recreation program, Special Olympics	20%	26%	27%	1.90	
State Developmental Disabilities, Ombudsman's, Department of Human Services or Department of Health Office	25%	24%	24%	0.07	
Self-advocacy group for people with disabilities	27%	22%	22%	1.56	
College or University	12%	20%	22%	5.97	**
Library	25%	21%	17%	4.88	**
Developmental Disability Council	15%	19%	19%	1.26	
Vocational Rehabilitation Service	12%	20%	16%	3.77	*
Religious organization	18%	15%	16%	0.62	
Protection and Advocacy Office (Law)	18%	16%	14%	1.07	
Centers for Independent Living	12%	15%	13%	0.95	
Cultural center or organization	3%	3%	3%	0.23	
Other	8%	7%	6%	0.45	
None/I don't Know	6%	3%	2%	7.76	***
					b,c < a

n = 2082; *** p < .001, ** p < .01, * p < .05

Groups that are more likely to use the source

ns although overall differences were found, none were significant in follow up tests

Items endorsed by more than 1/3 of respondents are shown in green

Note: When interpreting this table remember that respondents may not classify organizations as advocacy, support groups, disability organizations, community organizations, or parent centers in the same way that you do.

Table 8 Current supports received by disability group, age group and household income												
Which of the following service(s) does your family member with a disability currently receive?	% Yes	Disability Group						Age Group				
		a	b	c	F	Sig	Comparisons	12 to 16	17 to 22	F	Sig	
		IDD	ASD	Other								
School (Kindergarten through grade 12)	67%	67%	71%	61%	8.39	***	c < a,b	85%	44%	428.93	***	
Health insurance coverage	48%	51%	49%	43%	4.78	**	c < b,a	50%	46%	2.69		
Case management or service coordination	42%	54%	40%	27%	51.83	***	c < b < a	37%	48%	21.36	***	
Medicaid	41%	56%	36%	28%	61.12	***	c < b < a	36%	48%	27.44	***	
Behavioral or mental health services	35%	22%	43%	40%	45.82	***	a < b,c	38%	31%	9.94	**	
Specialist services such as occupational, physical or speech therapy	31%	39%	31%	20%	28.76			36%	22%	41.69		
					***		c < b < a				***	
Respite care/family support	26%	35%	26%	13%	44.27	***	c < b < a	25%	28%	1.47		
Parent training and education	23%	22%	24%	22%	0.58			25%	19%	8.67	**	
Supports at home (such as a home health aide, or personal care attendant)	17%	26%	13%	9%	37.75			13%	21%	18.50		
					***		b,c < a				***	
Assistive technology (e.g., augmentative communication device)	16%	22%	12%	12%	16.23	***	b,c < a	16%	15%	0.67		
Adaptive aids or equipment	12%	22%	4%	11%	58.66	***	b < c < a	13%	12%	0.29		
Job coach, employment or vocational rehabilitation services	10%	12%	9%	9%	2.60			2%	20%	178.89	***	
School (Technical, vocational, community college, college, university)	10%	8%	9%	12%	3.68			2%	20%	166.50		
					*		a,b < c				***	
Specialized transportation services	8%	12%	8%	4%	13.86	***	c < b < a	7%	11%	10.98	***	
Environmental modifications (including modifications to the person's home or vehicle)	7%	13%	3%	7%	29.71			7%	8%	1.64		
					***		b < c < a					
Supports to help my family member live in his/her own home (such as budgeting help, shopping, or meal planning)	5%	5%	4%	5%	0.18			2%	7%	26.63		
Out-of-home residential supports (such as a foster home or group home)	4%	4%	4%	4%	0.18			3%	4%	1.61		
Non-vocational day program for adults	3%	5%	1%	1%	11.68	***	b,c < a	0%	5%	46.31	***	
Homemaker/chore services	2%	3%	2%	1%	4.46	*	b,c < a	1%	3%	8.31	**	
Other	8%	9%	8%	7%	1.22			8%	8%	0.31		
None of the above	4%	2%	3%	7%	14.36	***	a,b < c	3%	5%	4.02	*	

N = 2064; *** p < .001, ** p < .01, * p < .05

Groups that are more likely to use the source

Items endorsed by more than 1/3 of respondents are shown in green

Table 8 Current supports received by disability group, age group household income

Which of the following service(s) does your family member with a disability currently receive?	Household Income(in \$,000s)					
	a	b	c			
	LT \$20	\$20 to \$50	MT \$50	F	Sig	Comparisons
School (Kindergarten through grade 12)	67%	68%	67%	0.14		
Health insurance coverage	30%	41%	56%	33.51	***	a < b < c
Case management or service coordination	34%	45%	41%	3.88	*	a < b
Medicaid	50%	49%	35%	20.91	***	c < a,b
Behavioral or mental health services	37%	33%	34%	0.56		
Specialist services such as occupational, physical or speech therapy	28%	30%	32%	0.95		
Respite care/family support	24%	28%	26%	0.69		
Parent training and education	19%	24%	24%	1.49		
Supports at home (such as a home health aide, or personal care attendant)	15%	17%	18%	0.33		
Assistive technology (e.g., augmentative communication device)	16%	14%	17%	1.17		
Adaptive aids or equipment	11%	12%	13%	0.40		
Job coach, employment or vocational rehabilitation services	7%	10%	10%	1.45		
School (Technical, vocational, community college, college, university)	6%	8%	11%	3.37		
Specialized transportation services	10%	8%	8%	0.25		
Environmental modifications (including modifications to the person's home or vehicle)	6%	5%	9%	5.46	**	b < c
Supports to help my family member live in his/her own home (such as budgeting help, shopping, or meal planning)	9%	5%	3%	6.43	**	b,c < a
Out-of-home residential supports (such as a foster home or group home)	5%	4%	3%	1.10		
Non-vocational day program for adults	2%	3%	3%	0.14		
Homemaker/chore services	5%	2%	2%	3.74	*	b,c < a
Other	13%	8%	8%	3.21	*	b,c < a
None of the above	5%	3%	4%	1.48		

N = 2064; *** p < .001, ** p < .01, * p < .05

Groups that are more likely to use the source

Items endorsed by more than 1/3 of respondents are shown in green