2017 Family and Individual Needs for Disability Supports (FINDS) Survey

The Arc of the United States, in collaboration with the Research and Training Center on Community Living at the University of Minnesota, is conducting this survey. The Arc is a national disability organization whose mission is to promote and protect the human rights of people with intellectual and developmental disabilities (IDD) and actively support their full inclusion and participation in the community throughout their lifetimes. The Research and Training Center on Community Living is a national research and training center that conducts research to change policy and practice in community living for people with intellectual and developmental disabilities.

There are an estimated 4.7 million people in the United States with an intellectual or developmental disability, about 1.3 million receive supports and services under the auspices of state IDD agencies. There were an estimated 1.7 million informal caregivers in the US in 2015 who provide daily assistance to fragile seniors, people with disabilities, and others who need help to live at home. Caregiving includes paid supports, but it also includes the many unpaid and informal supports that family and friends might do for a loved one who needs assistance. Caregiving might include running errands, attending medical appointments, preparing meals, etc. It also might include providing care for a child beyond what is typical for a child of that age. The number of informal caregivers number will significantly increase in coming years as “baby boomers” age, but little is known about how to help and sustain caregivers despite their importance to the health and well-being of so many people.

Within this larger group of caregivers are thousands of families and other caregivers who make it possible for most people with IDD to live and participate in community life throughout the U.S. These caregivers and the family members they support are not part of the formal system of human service agencies, but without their assistance, many people with IDD might be at risk for out of home placement in group homes or other congregate care living situations. As this group grows, it will be increasingly important to learn how to sustain caregivers in their vital role.

This survey seeks information from caregivers to answer the following questions:

* What are the life experiences of caregivers and their family members with IDD?
* What are the most difficult or stressful aspects of caregiving and what is rewarding?
* What would make life easier or better for caregivers, their families, and people with IDD they support across the life course?

As a caregiver of a person with IDD, your participation in this survey will teach us how to better support you and your family. Survey results will be used to inform policy makers, researchers, and service providers about what will help you in your role as a caregiver and what will best support your family. Your responses will not be connected to you personally; your information will be anonymous and confidential. Results will be presented in aggregate to protect the privacy of you and your family.

Your identity will remain unknown to staff working on this project unless you choose to provide your name and contact information at the end of this survey. There are no known risks or costs associated with completing this survey. Your completion and submission of this survey indicates that you are at least 18 and voluntarily consent to participating.

The average time to complete this survey is 30 to 45 minutes. Copies of this survey are available upon request in Spanish or alternate formats. Please contact Lynda Lahti Anderson at [LLA@umn.edu](mailto:LLA@umn.edu) or 612-626-7220 for copies of the survey in Spanish or an alternate format.

If you have further questions about the survey, please contact:

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# Family and Individual Needs Survey 2017

The intended participant of this survey is a family member or an unrelated caregiver who provides primary and frequent support to a person with an intellectual or developmental disability (IDD) living in the United States or its territories. Please submit only one survey per household. Please do not complete this survey if your primary relationship with an individual or individuals with intellectual disabilities is as a direct support professional or paid caregiver for that individual(s).

Since relationships and roles change over time, in the survey we refer to parents, family members, and unrelated caregivers as "caregivers” or “supporters." We use the terms “person/people with IDD” and "individual(s) or person/people receiving support” throughout the survey to refer to the person with Intellectual / Developmental Disabilities.

Background Question 1. Are you a paid caregiver to any adults or children with intellectual or developmental disabilities residing in in an institutional or group setting, like an ICF/ID, a developmental center, a residential school, a group home or apartment, or a nursing home?

* a. Yes (Please, do not complete the survey if you do not live with a person with IDD for whom you are a caregiver.)
* b. No (Please answer Background Question 2.)

Background Question 2. In the last 12 months, have you provided support to any child/children under the age of 18 because of a medical, behavioral, or other condition or disability? (This kind of unpaid care is more than the typical care required for a child of that age. This could include care for an ongoing medical condition, emotional, behavioral, or developmental concerns).

* a. Yes (Skip to Part 1 of the survey: About You and the Person You Support.)
* b. No (Please answer Background Question 3.)

Background Question 3. At any time in the last 12 months, have you provided support to an adult relative or friend 18 years or older with an intellectual or developmental disability (IDD) to help them take care of themselves? (This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.)

* a. Yes (Please move to Part I of the survey: About You and the Person You Support.)
* b. No (Please do not complete the survey.)

## PART 1: ABOUT YOU AND THE PERSON YOU SUPPORT

**Please tell us about the amount of caregiving you provide to person(s) with IDD.**

1. In the last 12 months, how many child/children under the age of 18 because of a medical, behavioral, or other condition or disability did you support? (This kind of unpaid care is more than the typical care required for a child of that age. This could include care for an ongoing medical condition, emotional, behavioral, or developmental concerns)**.**

* a. 0 (Skip to question 3)
* b. 1
* c. 2
* d. 3
* e. 4
* f. 5
* g. More than 5

1. Please select the option that best describes the number of hours of support that you provide to the child(ren) each week:
   * a. 9 or fewer
   * b. 10 to 20 hours per week
   * c. 21 to 30 hours per week
   * d. 10 to 40 hours per week
   * e. 41 – 80 hours per week
   * f. More than 80 hours per week
2. In the last 12 months, how many adult relatives or friends 18 years or older with an intellectual or developmental disability (IDD) did you support? (This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.

* a. 0 (Skip to question 5)
* b. 1
* c. 2
* d. 3
* e. 4
* f. 5
* g. More than 5

1. Please select the option that best describes the number of hours of support that you provide to the adult(s) each week:
   * a. 9 or fewer
   * b. 10 to 20 hours per week
   * c. 21 to 30 hours per week
   * d. 31 to 40 hours per week
   * e. 41 – 80 hours per week
   * f. More than 80 hours per week
2. Does the person with IDD that you support have a court-appointed legal guardian?
   * a. Yes
   * b. No (Skip to question 8)
3. Do you serve as a court-appointed legal guardian to the adult(s) indicated above?
   * a. Yes
   * b. No (Skip to question 8)
4. Prior to obtaining legal guardianship, did you explore any other options?
   * a. Yes (Skip to part c)
   * b. No (skip to question 8)
   * c. If you selected yes, please check the options you explored:

|  |  |  |
| --- | --- | --- |
| **Option** | **Yes** | **No** |
| a. Representative Payee |  |  |
| b. Supported decision making |  |  |
| c. Power of Attorney |  |  |
| d. Informal guidance or advice |  |  |
| e. Other, please specify: | | |

**To help policy makers to understand the situation of caregivers, we need to ask some basic questions about you – remember this information is anonymous and confidential!**

1. What is your gender?

* a. Male
* b. Female
* c. Other
* d. Prefer not to answer

1. What is your 5-digit zip code? \_\_ \_\_ \_\_ \_\_ \_\_

9.b What is your state? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. With which race do you primarily identify? (Pick one)

* a. White/Caucasian
* b. Black or African American
* c. American Indian or Alaskan Native
* d. Asian
* e. Native Hawaiian or Pacific Islander
* f. Other race (print race) \_\_\_\_\_\_\_\_\_\_\_\_\_
* g. Two or more races
* h. Prefer not to answer

1. Are you of Hispanic or Latino origin?

* a. Yes (Answer part d)
* b. No (Skip to question 12)
* c. Decline to answer (Skip to question 12)

d. If yes, what is your Hispanic/Latino origin (Pick one)?

\_\_Mexican, Mexican American, Chicano

\_\_Puerto Rican

\_\_Cuban

\_\_Central or South American

\_\_Other Hispanic, Latino or Spanish origin.

Specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_Not sure

\_\_Prefer not to answer

1. What is your primary language?

* a. English
* b. Spanish
* c. Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. What is your age in years? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. Where were you born?
   * a. United States (Skip to Question 16)
   * b. Other country (Please specify country of origin) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
3. How many years have you lived in US? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
4. How many adults (ages 18 and older), including yourself, are in your household?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_

16b. How many children (17 and younger) are in your household?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Are you paid to give support (support for day-today activities beyond what one would typically expect for a person of that age) to the person(s) with IDD?
   * a. Yes. (Answer part c)
   * b. No (Skip to question 18)

c. If you selected yes, please answer the following:

i. I provide \_\_\_\_ (number) of hours of support per week.

ii. I am paid at an average pay rate of $\_\_\_\_ per hour to provide that

support. ($xx.xx)

1. Are any other family members or informal caretakers paid to give support/care to the person(s) with IDD?

* a. Yes. (Answer part c)
* b. No (Skip to question 19)

c. If you selected yes, please answer the following:

i. S/he/they provide \_\_\_\_\_\_ (number) of hours of support per week.

ii. S/he/they are paid at an average pay rate of $\_\_\_\_\_\_\_\_ per hour to provide that support. ($xx.xx).

1. Currently, or within the past 12 months do/did you do any work for pay or profit outside of giving support/care to the person with IDD?
   * a. Yes. I am/was employed by someone else. (Skip to question 20)
   * b. Yes. I am/was self-employed. (Skip to question 20)
   * c. No. (Answer part d)
2. Since you did not work for pay or profit outside of giving support/care to the person with IDD, please select the option that best describes your employment situation:
   * i. Unemployed
   * ii. Retired
   * iii. Disabled
   * iv. Unable to work due to providing support for person with IDD
   * v. Quit work to provide supports for person with IDD
   * vi. Student
   * vii. Other reason unable to work (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

*If you answered no to question 19, please skip to question 23.*

1. Currently or when working in the past 12 months, on average, how many hours do you/did you typically work for pay or profit every week in a job that is/ was not associated to providing supports to the person?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Hours per week

1. Currently or when working in the past 12 months, on average what was your hourly average pay rate?

$\_\_\_\_\_\_\_ dollars per hour. ($XX.XX)

1. Currently or when working in the past 12 months and providing support to the person with IDD, which of the following did your employer offer:

|  |  |  |
| --- | --- | --- |
| **Employer Work Conditions** | **Yes** | **No** |
| a. Flexible work hours |  |  |
| b. Telecommuting or working from home |  |  |
| c. Access to helpful information, referrals, or counseling or an employee assistance program to help caregivers like you |  |  |
| d. Paid leave, where you could take paid time off to support for your family member |  |  |
| e. Paid sick days |  |  |
| f. Other benefit or work condition that was helpful to you as a caregiver? Please specify: |  |  |

1. Are you currently or within the past 12 months when you were last providing support in the following relationship status?

* a. Married
* b. Living with a partner
* c. Widowed
* d. Separated
* e. Divorced
* f. Single, never married
* g. Prefer not to answer

1. What is the highest level of education you have completed?
   * a. Kindergarten
   * b. 1st grade
   * c. 2nd grade
   * d. 3rd grade
   * e. 4th grade
   * f. 5th grade
   * g. 6th grade
   * h. 7th grade
   * i. 8th grade
   * j. 9th grade
   * k. 10th grade
   * l. 11th grade
   * m. 12 grade, no diploma received
   * n. High School Diploma or GED
   * o. Some college
   * p. Bachelor’s degree
   * q. Post-graduate education
   * r. Prefer not to answer
2. What was your gross (before taxes) household income in the past year? To the best of your knowledge, please include income from all sources including wages, social security, retirement benefits, interest etc. (You can estimate your gross income, or you can find your “gross income” on the most recent tax return that you filed.)

$ \_\_\_\_\_\_\_\_\_\_\_\_ ($XX,XXX)

**About the Person You Support**

**Now we would like to get some information about the person with IDD that you support currently or have supported in the past 12 months. If you provide support to more than one person, please think about the person for whom you provide/provided the MOST hours of support, and answer the questions with this person in mind.**

1. What is the person’s gender?

* a. Male
* b. Female
* c. Other
* d. Prefer not to answer

1. How long have you been providing support to this person?
   * a. Less than one year
   * b. 1-5 years
   * c. 6-10 years
   * d. 11-15 years
   * e. 16-20 years
   * f. 21-25 years
   * g. 26-30 years
   * h. More than 30 years
2. What is this person’s age in years? \_\_\_\_\_\_\_\_\_\_\_\_\_
3. What is ***your*** primary relationship with the person with IDD?

* a. Parent
* b. Child
* c. Grandparent
* d. Sibling
* e. Spouse/Partner
* f. Aunt/Uncle
* g. Foster parent
* h. Friend
* i. Neighbor
* j. Other (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. With which race does the person with IDD you support primarily identify? (Select one)

* a. White/Caucasian
* b. Black or African American
* c. American Indian or Alaskan Native
* d. Asian
* e. Native Hawaiian or Pacific Islander
* f. Other race (print race) \_\_\_\_\_\_\_\_\_\_\_\_\_
* g. Two or more races
* h. Prefer not to answer

1. Is the person you support of Hispanic or Latino origin?

* a. Yes (Answer part d)
* b. No (Skip to question 32)
* c. Prefer not to answer (Skip to question 32)
* d. If yes, what is your Hispanic/Latino origin (Pick one)?
  + - i. Mexican, Mexican American, Chicano
    - ii. Puerto Rican
    - iii. Cuban
    - iv. Central or South American
    - v. Other Hispanic, Latino, or Spanish origin. Specify: \_\_\_\_\_\_\_\_\_\_
    - vi. Not sure
    - vii. Prefer not to answer

1. What is the primary language of the person you support?

* a. English
* b. Spanish
* c. Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. What type(s) of disability does the person have? (Please select ALL conditions that the person has).
   * a. Adaptive development is delayed – adaptive skills and behaviors are those needed to complete every day skills like peers of the same age
   * b. Cognitive development is delayed
   * c. Communication is delayed
   * d. Has a diagnosed physical or mental condition that has a high chance of resulting in developmental delay
   * e. Physical development is delayed
   * f. Social or emotional development is delayed
   * g. Not sure, but “early intervention” is/was recommended

h. Autism Spectrum Disorder (includes Asperger’s, Autism, Pervasive Developmental Disability Not Otherwise Specified)

* + i. Alzheimer’s/Other forms of dementia
  + j. Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD)
  + k. Cerebral Palsy
  + l. Deaf/Hard of hearing
  + m. Down Syndrome
  + n. Fetal Alcohol Spectrum Disorder
  + o. Blind/Limited vision
  + p. Epilepsy/seizure disorder or other neurological condition
  + q. Mental/behavior/psychiatric diagnosis (such as anxiety, depression, mood disorder, bi-polar, schizophrenia)
  + r. Intellectual disability (formerly referred to as mental retardation)
  + s. Specific learning disability (such as dyslexia or auditory processing disorder)
  + t. Physical disability or mobility limitation (orthopedic, paralysis, loss of limb)
  + u. Speech or language limitation (such as apraxia or aphasia)
  + v. Traumatic brain injury
  + w. Other developmental delay, please specify:
  + x. Other health impairment, please specify:
  + y. Not sure, but it requires specialized support, please specify:

**Please tell us about the living arrangements of the person you support.**

1. Do you currently live with the person you are supporting?
   * a. Yes (skip to question 41)
   * b. No
2. What is the person’s 5-digit zip code? \_\_ \_\_ \_\_ \_\_ \_\_

35 b. What is the person’s state? \_\_\_\_\_\_\_\_\_\_\_\_\_

1. Please select the category that best describes the person’s present living situation.

* a. Homeless (Skip to question 41)
* b. The home of a family member or friend (other than you). (Skip to question 39)
* c. With a foster family or host family (Skip to question 39)
* d. An apartment or house that s/he OWNS or RENTS and lives with his or her own family (spouse, partner, or children) (skip to question 37)
* e. An apartment or house that s/he OWNs or RENTS and lives alone, with housemates, or with support staff. (skip to question 37)
* f. A supervised group home with three or fewer people with disabilities (Skip to question 38)
* g. A supervised group home with four to six people with disabilities (Skip to question 38)
* h. A supervised group residence with seven to fifteen people with disabilities (Skip to question 39)
* i. A supervised group residence or facility with more than fifteen people with disabilities (such as a developmental center) (Skip to question 39)
* j. An intentional community where people with and without disabilities live cooperatively (such as L ’Arche or Camphill) (Skip to question 39)
* k. A planned community where only people with IDD live (such as a farmstead, or disability -specific housing communities, such as those for people with ASD) (Skip to question 37)
* l. A boarding home or board and care facility (Skip to question 39)
* m. An institution such as a nursing home or psychiatric hospital or facility (Skip to question 39)
* n. Military housing (Skip to question 39)
* o. A school dormitory (preschool through high school) (Skip to question 39)
* p. A school dormitory (post-high school such as a college or trade school) (Skip to question 39)
* q. Other (please specify)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (Skip to question 38)

1. If s/he lives in his/her own home, does s/he receive support in his/her home?
   * a. Yes
   * b. No
2. Does the person with IDD own the property?
   * a. Yes
   * b. No
   * c. Do not know
3. Approximately, what is the travel time to your home?
   * a. 20 minutes or less
   * b. 21 minutes to an hour
   * c. 1-2 hours
   * d. More than 2 hours
4. How often do you visit?
   * a. Daily
   * b. More than once a week
   * c. Once a week
   * d. A few times a month
   * e. A few times a year
   * f. Once a year or less
5. What do you believe is the ideal living arrangement for the person with IDD? If the person with IDD is a child, please indicate the ideal for their life as an adult.

* a. Where s/he lives right now
* b. In someone else’s home, like a family member
* c. In an apartment or house that s/he OWNs
* d. In an apartment or house that s/he RENTs
* e. In military housing
* f. In a boarding home
* g. In a group home with three or fewer other people with disabilities that s/he is not related to
* h. In a group home with four to six other people with disabilities that s/he is not related to
* i. In a residence that has seven to fifteen other people with disabilities that s/he is not related to
* j. In a residence that has more than fifteen other people with disabilities that s/he is not related to
* k. In an apartment building or intentional community living situation that includes both people with disabilities and those without
* l. In an apartment building or community living situation that includes only people with disabilities
* m. In a nursing home
* n. In an institution/developmental center
* o. Other (Please specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. What is the ideal living arrangement for the person with IDD in terms of whom they should live with? If the person is a child, state your preference for how they should live as an adult.

* a. Live alone
* b. One or both parents, while living
* c. Sibling or other family member
* d. Roommates that s/he is assigned
* e. Roommates that s/he chooses
* f. Other (please specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Please tell us your views about the educational experiences of the person you support.**

1. Please check the following boxes which best describe the settings in which the person with IDD attends, or previously attended, school.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Education Level-Attained** | **Public** | **Private** | **Home School** | **Not there yet** | **Do not know** |
| a. Early-Intervention |  |  |  |  |  |
| b. Pre-k |  |  |  |  |  |
| c. Kindergarten |  |  |  |  |  |
| d. Primary School |  |  |  |  |  |
| e. Middle School |  |  |  |  |  |
| f. High School |  |  |  |  |  |

1. For the level of school that the person with IDD, or previously attended, please check the boxes that best describe whether s/he was fully, partially or not included with students without disabilities, or whether the school includes only students with disabilities.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Fully included** | **Partially included** | **Not included** | **Only students with disabilities** | **Not there yet** | **Do not know or N/A** |
| a. Early-Intervention |  |  |  |  |  |  |
| b. Pre-k |  |  |  |  |  |  |
| c. Kindergarten |  |  |  |  |  |  |
| d. Primary School |  |  |  |  |  |  |
| e. Middle School |  |  |  |  |  |  |
| f. High School |  |  |  |  |  |  |

1. What is the highest level of education completed by the person you support?

* a. Kindergarten
* b. 1st grade
* c. 2nd grade
* d. 3rd grade
* e. 4th grade
* f. 5th grade
* g. 6th grade
* h. 7th grade
* i. 8th grade
* j. 9th grade
* k. 10th grade
* l. 11th grade
* m 12 grade, no diploma received
* n. High School Diploma or GED
* o. Some college
* p. Bachelor’s degree
* q. Post-graduate education
* r. Prefer not to answer

1. Overall, how satisfied are you with the quality of education that the person with IDD received or is receiving at each education level?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Very dissatisfied** | **Dissatisfied** | **Satisfied** | **Very satisfied** | **Not applicable** |
| a. Pre-K |  |  |  |  |  |
| b. Elementary (K-6) |  |  |  |  |  |
| c. Middle School |  |  |  |  |  |
| d. High School |  |  |  |  |  |
| e. Post-secondary |  |  |  |  |  |

1. Do you think it is important for the person you care for/support to continue his/her education after high school or go back to school as an adult to learn new things?
   * a. Not important
   * b. Somewhat important
   * c. Very important
2. Which of the following do you think are important reasons why the person you support might take classes at a local community college, university, or trade or technical school?

|  |  |  |
| --- | --- | --- |
| **Reason** | **Yes** | **No** |
| * 1. To learn about things they are interested in |  |  |
| * 1. To obtain a non-credit skill/certificate/certificate of completion |  |  |
| * 1. To learn how to use transportation options |  |  |
| * 1. To gain experiences that will help them get a job |  |  |
| * 1. To obtain a credit-based degree or certification |  |  |
| * 1. To fulfill IEP plans |  |  |
| * 1. To have a college experience like non-disabled peers |  |  |
| * 1. To learn job-related skills |  |  |
| * 1. To earn a GED/high school diploma |  |  |
| Other, please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | |

**Please tell us about the employment experiences of the person you support.**

1. Does the person with IDD have a job for which they earn pay?
   * a. Yes (Skip to question 52)
   * b. No
2. What does the person you support do during the day/typical work hours?
   * a. Stays home (does not attend a formal day program or participate in employment)
   * b. Participates in unpaid community activity/activities (such as volunteering or community-based activity)
   * c. Unpaid facility-based activity (such as a day program)
   * d. Still in school
3. Does the person want a job for which they receive pay?
   * a. Yes (Skip to question 62)
   * b. No (Skip to question 62)
4. Does the person receive at least minimum wage or above (federal minimum wage is $7.25/hour)?
   * a. Yes
   * b. No
5. What is the person’s hourly wage? \_\_\_\_\_\_\_\_\_ ($XX.XX)
6. What type of job does this person have?
   * a. Integrated employment (competitively employed in a setting not specifically for people with disabilities earing at least minimum wage; working at a “regular job”)
   * b. Paid facility-based employment (such as a sheltered workshop)
   * c. Community-based group employment (enclave)
   * d. Self-employment
7. How satisfied is the person with their current work setting?
   * a. Very dissatisfied
   * b. Dissatisfied
   * c. Satisfied
   * d. Very satisfied
8. If the person with IDD has a paid job, what kinds of supports do they receive?
   * a. None
   * b. Individual employment support
   * c. Group employment support
   * d. Other
9. What type of work does the person engage in?
   * a. Facility maintenance, janitorial, cleaning
   * b. Landscaping, grounds maintenance
   * c. Animal care
   * d. Child care
   * e. Food service
   * f. Office work
   * g. Retail
   * h. Professional work (such as public speaking)
   * i. Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
10. How satisfied with the type of work s/he does?

* a. Very dissatisfied
* b. Dissatisfied
* c. Satisfied
* d. Very satisfied

1. How satisfied is the person with their pay?

* a. Very dissatisfied
* b. Dissatisfied
* c. Satisfied
* d. Very satisfied

1. How many hours, on average, does the person work in a 2-week pay period?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Does the person receive employment benefits? (Skip to question 64)
   * a. Yes
   * b. No

**Please tell us about the person with IDD’s experience with technology.**

1. Which of the following technology devices does the person own?

|  |  |  |
| --- | --- | --- |
| **Device** | **Yes** | **No** |
| a. Smartphone (such as an iPhone or a similar device) |  |  |
| b. Laptop/desktop computer |  |  |
| c. Tablet (such as an iPad or a Surface) |  |  |
| d. Smart home technology (such as sensors, voice activated switches, or smartphone enabled controls) |  |  |
| e. Picture communication software (enables use of pictures and symbols to communicate) |  |  |
| f. Wearable technology |  |  |
| g. Console video games system (such as Xbox, PlayStation or Wii) |  |  |
| h. Other, please specify | | |

1. Does the person with IDD have assistance available when needed to troubleshoot and update the device?
   * a. Yes
   * b. No
   * c. Do not know
2. Does the person have access to broadband internet at their place of residence?
   * a. Yes
   * b. No
   * c. Do not know
3. Does the person with IDD use the following websites or online services?

|  |  |  |
| --- | --- | --- |
| **Service** | **Yes** | **No** |
| a. Email (Such as Hotmail or Gmail) |  |  |
| b. Web search (such as Google) |  |  |
| c. Social media (such as Facebook, Snapchat, Twitter, etc.) |  |  |
| d. News or weather websites |  |  |
| e. Online shopping (such as Amazon) |  |  |
| f. Online maps |  |  |
| g. Online games |  |  |
| h. Online job applications |  |  |
| i. Online dating |  |  |
| j. Other, please specify | | |

**ACCESS, UTILIZATION AND GAPS IN SERVICE AND SUPPORT**

**This section of the survey looks at the services and support that the person with IDD receives. Remember to answer the questions with just one person in mind – the person for whom you provide the most hours of support.**

1. Is there a place that the person with IDD USUALLY goes when she/he needs routine preventative health care, such as a physical examination?
   * a. Yes
   * b. No (Skip to question 68)
   * c. Do not know (Skip to question 68)
2. Where does the person typically go for routine, preventative health care?
   * a. Doctor’s office
   * b. Hospital emergency room
   * c. Hospital or outpatient department
   * d. Clinic or Community Health Center
   * e. School (nurse’s office, athletic trainer’s office, etc.)
   * f. Friend/relative
   * g. Location outside of the U.S.
   * h. Some other place, please specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
   * i. Does not go to one place most often
   * j. Does not know
3. A personal doctor or nurse is a health professional who knows the person with IDD will and is familiar with the person’s health history. This can be a general doctor, a specialist doctor, a nurse practitioner, or a physician’s assistant. Do you have one person you think of as the personal doctor or nurse for the person with IDD?
   * a. Yes
   * b. No (Skip to question 71)
   * c. Do not know (Skip to question 71)
4. Who is the one person the individual with IDD uses as his/her personal doctor or nurse?
   * a. General doctor (general practice, pediatrician, family or internal medicine)
   * b. Specialist
   * c. Nurse Practitioner
   * d. Physician’s Assistant
   * e. Other, please specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
   * f. Do not know
5. How often does the person’s primary healthcare provider, who you indicated above, take into account the wishes of the person with IDD and/or your wishes?
   * a. Never
   * b. Rarely
   * c. Sometimes
   * d. Usually
   * e. Always
6. The table below lists different types of support that you may provide.

* In column 1 read the support description and answer “yes” if you provide this type of support or “no” if you don’t.
* In column two if you DO provide this support circle the number (1 through 5) that best describes how difficult it is for you to provide this support. Do not select a number if you do not provide this type of support.
* In column 3 tell us if the person with IDD needs this support (if not currently receiving) or more of this type of support than s/he is currently receiving

| **Column 1** | **Column 2** | | | | | **Column 3** | |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Which of these support activities do YOU help the person with?** | **Select the number that best describes the level of difficulty you experience with this task.** | | | | | **Does the person need this support or more of this type of support than s/he currently receives?** | |
| **Not at all Difficult**  **1** | **A Little Difficult**  **2** | **Somewhat Difficult**  **3** | **Difficult**  **4** | **Very**  **Difficult**  **5** | **Yes** | **No** |
| 1. Getting in and out of beds or chairs   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Getting dressed/undressed   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Getting to and from the toilet   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Bathing/Showering/Grooming   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Post-toileting hygiene/diapers   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Assistance with eating   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Mobility (walking, standing, getting in and out of bed, adjusting position in bed/ wheelchair)   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Giving medications   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Following up with OT, PT or other treatments at home   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Making decisions about everyday matters such as what to wear or when to go to bed   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Managing finances such as banking, paying bills or filling out forms   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Doing errands, grocery or other shopping   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Housework such as doing dishes, laundry or straightening up   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Preparing simple meals or arranging for meals   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Doing simple home upkeep such as changing bulbs, tightening screws   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Transportation, either by driving or helping to arrange rides   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Employment, career, or educational support including finding and keeping a job or volunteering   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Obtaining day activities such as recreational programs   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Finding specialists and coordinating those services   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Finding personal care assistants, aides or direct support professionals   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Finding respite services to enable the person with IDD and the caregiver to have some time apart   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. If the person you support is under 18, finding childcare/after-school care   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Advocacy and supporting self-advocacy   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Noting progress and making changes if needed   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Communicating with other support and healthcare professionals about progress and needs   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Organizing and prioritizing tasks   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Crisis prevention/ intervention including such things as managing behavioral or aggressive outbursts, or self-injurious behavior   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Arranging for federal or state entitlements (benefits) or managing entitlements   such as social security  \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Obtaining person-centered planning and support   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Arranging social and leisure activities   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Providing direct financial support   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Obtaining environmental modifications and technology   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Performing medical tasks such as feeding with a tube, suctioning, monitoring respiration   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Self-directing services such as supervising and paying wages to in-home workers   \_\_\_ Yes \_\_\_ No | 1 | 2 | 3 | 4 | 5 |  |  |
| 1. Other, please describe: | 1 | 2 | 3 | 4 | 5 |  |  |

1. What are the top 3 priority supports for the person with IDD that you provide?
   * a. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
   * b. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
   * c. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. Please circle the number that best describes whether your household is currently receiving any of the following supports and services? If your household IS receiving this support, please use the last column to rate the service/support quality

| **Type of Support** | **Yes** | **Yes, but need more** | **No, not needed** | **No, but needed** | **If yes - rate its quality** | | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Very bad** | **Somewhat bad** | **Neither good nor bad** | **Somewhat good** | **Very Good** |
| a. Inclusive childcare/ aftercare/ summer care | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| b. Accessibility supports at home, work or in educational settings? This includes adaptive equipment, workplace accommodations, learning supports, etc. | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| c. Advocacy services and training | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| d. Assistance with complex health needs | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| e. Day program/day supports such as leisure, retirement employment supports/volunteer activity | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| f. Competitive integrated employment (for at least minimum wage) | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| g. Early Intervention for ages 0-3 | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| h. Family to family connecting activities like support groups, parent-to-parent networks, advocacy organizations, etc. | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| i. Financial Support – you receive money (cash, stipends, vouchers, or reimbursement) NOT including SSI payments | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| j. Help with navigating, coordinating and planning services | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| k. In-Home Support – People come to your home to assist the person with IDD. | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| l. Inclusive programs including post-secondary education, recreation, sports, etc. | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| m. Information about entitlements, IDD services/ technology, law and policies | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| n. Legal services | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| m. Mental/ behavioral health care or other therapies (such as physical, or occupational, etc. | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| n. Respite Care – someone else supports the person with IDD to give you a break. | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| o. Residential supports outside of your home | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| p. Social Security Benefits – SSI payments, survivor benefits etc. | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |
| q. Transportation to go to work, day program, medical visits etc. | 3 | 2 | 0 | 1 | 1 | 2 | 3 | 4 | 5 |

1. What are the top 3 supports and services that are important for this person’s well-being?
   * a. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
   * b. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
   * c. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. Approximately how much out-of-pocket money did you spend last year on this person’s medical services, equipment, supplies, therapies, and other supports/services?
   * a. None
   * b. $1 - $100
   * c. $101-$1,000
   * d. $1,001 to $5,000
   * e. $5,001 to $10,000
   * f. More than $10,000
   * g. Prefer not to answer
3. Are you noticing that support services in your community are:
   * a. Increasing (Skip to question 78)
   * b. Staying about the same (Skip to question 78)
   * c. Decreasing
   * d. Do not know (Skip to question 78)
4. How has the life of the person with IDD been impacted by decreases in services?

|  |  |  |  |
| --- | --- | --- | --- |
| **Service** | **Yes** | **No** | **Not Applicable** |
| a. Schools have cut back on services like physical therapy, occupational therapy, and speech therapies |  |  |  |
| b. Day care/ before school/after-school care has cut back hours, closed or shut down |  |  |  |
| c. I am paying for more out-of-pocket. |  |  |  |
| d. S/he has lost our paid support person because there were no funds to pay for them. |  |  |  |
| e. I am providing more support than I used to. |  |  |  |
| f. S/he is not able to go outside the home as much as they used to do. |  |  |  |
| g. S/he does not see friends as much anymore. |  |  |  |
| h. S/he does not talk to as many people as they used to. |  |  |  |
| j. S/he does not get to choose what they want to do as much as they used to. |  |  |  |
| k. S/he has had work hours cut back. |  |  |  |
| l. S/he no longer has a job. |  |  |  |
| m. S/he no longer has a job coach. |  |  |  |
| n. S/he no longer has access to transportation services to take them places. |  |  |  |
| o. S/he does not visit the doctor as often, even if they need to |  |  |  |

1. Does the person with IDD have an individualized service plan (excluding educational plans)?
   * a. Yes
   * b. No (Skip to question 82)
   * c. Do not know (Skip to question 82)
2. Does the plan address all of the support that s/he needs?
   * a. Yes
   * b. No
   * c. Do not know
3. Did you and the person with IDD help to develop the plan?
   * a. Yes
   * b. No
   * c. Do not know
4. Why didn’t you and the person with IDD help to develop the plan?
5. Do you have a plan for the future that identifies who will support the person with IDD if you are not able to provide that support?
   * a. Yes
   * b. No
   * c. Do not know
6. Looking toward the future when you may not be able to support the person with IDD, are there any issues of potential concern?

|  |  |  |
| --- | --- | --- |
| **Issue** | **Yes** | **No** |
| a. There is no one else to provide the support I am giving |  |  |
| b. The quality of support will go down if I am not there to advocate |  |  |
| c. The person with IDD will be financially exploited if I cannot oversee finances |  |  |
| d. Some form of abuse or neglect might occur |  |  |
| e. His or her health will deteriorate |  |  |
| f. S/he will not have enough friends and social activities |  |  |
| g. I don’t know where s/he will live if not with me. |  |  |
| h. S/he will be moved to a congregate facility such as an institution, ICF/ID, or nursing home |  |  |
| i. S/he will have to live somewhere they don’t want to live |  |  |
| j. S/he will have difficulty advocating for what s/he needs |  |  |
| k. S/he will not be able to contribute to major life decisions or receive support for self-determination |  |  |
| l. Other, please specify: | | |

1. What source(s) of funds are used to pay for current care/support?

|  |  |  |
| --- | --- | --- |
| **Type of Support** | **Yes** | **No** |
| * 1. Support is provided by people who are unpaid |  |  |
| b. Social Security income benefit or state income benefit |  |  |
| c. Personal income of person with IDD - not from the state or federal government |  |  |
| d. Personal income of parent, family member or other caregiver - not from the state or federal government |  |  |
| e. Special Needs Trust |  |  |
| f. Personal savings of person with IDD |  |  |
| g. Personal savings of parent, family member or other caregiver |  |  |
| h. Medicaid Home and Community Based Waiver |  |  |
| i. Other Medicaid program |  |  |
| j. Private insurance |  |  |
| k. Other state or local government program, specify |  |  |
| l. Other, specify |  |  |

1. Is the person with IDD currently on a waiting list for government-funded services/supports?
   * a. Yes
   * b. No (Skip to question 88)
   * c. Do not know (Skip to question 88)
2. What service was requested? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
3. How long has the person with IDD been on the waiting list for this service?
   * a. Less than a year
   * b. 1 year
   * c. 2 years
   * d. 3-5 years
   * e. 6-10 years
   * f. More than 10 years
4. Which of the following interactions has the person with IDD had with the criminal justice system?

|  |  |  |
| --- | --- | --- |
| **Interaction** | **Yes** | **No** |
| 1. Victim of a crime |  |  |
| 1. Witness to a crime |  |  |
| 1. Suspect in a crime |  |  |
| 1. Defendant in a criminal charge |  |  |
| 1. Convicted of a crime |  |  |
| 1. Incarcerated upon conviction of a crime |  |  |
| 1. Other, please specify |  |  |
| 1. None -- this individual has not had any interactions with the criminal justice system |  |  |

1. Within the past year, has the person with IDD wandered off or become lost from home, someone else’s, home, school or work?
   * a. Yes
   * b. No
   * c. Do not know

| Each of the below tasks are related to finding and managing appropriate supports and services. For each, please select the response that best describes the level of ease or difficulty you have with the task. 90. Each of the below tasks are related to finding and managing appropriate supports and services. For each, plsponse that best describes the level of ease or difficulty you have with the task. **Task** | **No problem** | **Somewhat of a problem** | **A major problem** | **Not Applicable** |
| --- | --- | --- | --- | --- |
| 1. Finding resources to help with skills needed for adult life such as responsible sexuality, self-advocacy, and self-determination |  |  |  |  |
| 1. Finding affordable supported living/residential support |  |  |  |  |
| 1. Finding non-institutional, community-based support |  |  |  |  |
| 1. Dealing with breakdowns in support arrangements |  |  |  |  |
| 1. Finding out about legal issues such as guardianship, conservatorship, or estate planning |  |  |  |  |
| 1. Finding culturally sensitive resources |  |  |  |  |
| 1. Learning about best practices or finding resources that embrace best practices like person-centered planning |  |  |  |  |
| 1. Doing end of life planning |  |  |  |  |
| 1. Involvement in decisions about the support and services of the person I care for |  |  |  |  |
| 1. Addressing my own health issues |  |  |  |  |
| 1. Having enough money to pay for support |  |  |  |  |
| 1. Meeting my personal needs such as personal time, exercise, etc. |  |  |  |  |
| 1. Finding care so I can work |  |  |  |  |
| 1. Having someone to talk to that understands my concerns/fears |  |  |  |  |
| 1. Getting cooperation in assistance from other family members |  |  |  |  |
| 1. Balancing other family responsibilities (e.g., children, marriage, housework) |  |  |  |  |
| 1. Adjusting my work schedule, meeting my work responsibilities |  |  |  |  |
| 1. Dealing with dangerous, unwanted, or difficult behaviors of the person I support |  |  |  |  |
| 1. Dealing with in appropriate treatment of the person with IDD by the police or criminal justice system |  |  |  |  |
| 1. Addressing human rights violations or other concerns about the quality of support provided by others |  |  |  |  |
| 1. Helping my family member find friendships and inclusive community experiences through such things as work, volunteer activity, recreation, and membership in a church or other organization of interest |  |  |  |  |
| 1. Physically modifying my home to meet support requirements |  |  |  |  |

| What outcomes have you experienced in your role as a caregiver?**Outcome** | **Strongly Disagree** | **Somewhat Disagree** | **Somewhat Agree** | **Strongly Agree** |
| --- | --- | --- | --- | --- |
| 1. My family/household relationships have been strengthened |  |  |  |  |
| 1. I have developed new values about what is important in life |  |  |  |  |
| 1. I have become more spiritual or religious |  |  |  |  |
| 1. I am more relaxed and happy |  |  |  |  |
| 1. My quality of life is improved |  |  |  |  |
| 1. I am less reluctant to ask for help |  |  |  |  |
| 1. I am a source of hope and support for others |  |  |  |  |
| 1. I feel fortunate to have this life experience |  |  |  |  |
| 1. I take more time to not rush through life |  |  |  |  |
| 1. I appreciate others more than I used to |  |  |  |  |
| 1. I spend more time at home invested in family-oriented activities |  |  |  |  |
| 1. I have found new friends, work or interests that are also connected to IDD |  |  |  |  |
| 1. I have closer ties to people in my community |  |  |  |  |
| 1. I have noticed that people in my community are happy to see me and the person with IDD |  |  |  |  |
| 1. I am more aware of policy issues |  |  |  |  |
| 1. I vote |  |  |  |  |
| 1. I call my legislative representatives |  |  |  |  |
| 1. I am more involved in advocacy efforts and non-profit activities |  |  |  |  |
| 1. I enjoy helping other families and people with IDD |  |  |  |  |
| 1. The experience has led me to disability related education and/or career opportunities |  |  |  |  |
| 1. I am more confident, assertive and effective in my communications with others |  |  |  |  |
| 1. I worry a lot about my child's future |  |  |  |  |
| 1. I honestly believe I have the skills necessary to be a good parent to my child |  |  |  |  |
| 1. I feel physically strained/fatigued |  |  |  |  |
| 1. I feel loneliness or isolation |  |  |  |  |
| 1. I am under financial strain |  |  |  |  |
| 1. I am under emotional strain, guilt, depression |  |  |  |  |
| 1. Care giving interferes with work |  |  |  |  |
| 1. I am reluctant to ask for help |  |  |  |  |
| 1. I feel underappreciated |  |  |  |  |
| 1. I experience stress in close personal relationships |  |  |  |  |
| 1. I have difficulty finding time for the whole family |  |  |  |  |
| 1. I do not have sufficient time for myself |  |  |  |  |
| 1. I feel criticized by others |  |  |  |  |
| 1. I feel excluded from community activities or organizations |  |  |  |  |
| Other, please specify: | | | | |

1. What are the top 3 things that do, or might, help you to have a more positive outcome?
   * a. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
   * b. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
   * c. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. While you were a caregiver, did you also work?
   * a. Yes
   * b. No (Skip to question 94)
3. As a result of caregiving, did you ever experience any of these work related activities?

|  |  |  |
| --- | --- | --- |
| **Activity** | **Yes** | **No** |
| 1. Went in late, left early, or took time off during the day to provide care |  |  |
| 1. Took a leave of absence |  |  |
| 1. Went from working full-time to part-time or cut back your hours |  |  |
| 1. Turned down a promotion |  |  |
| 1. Lost any of your job benefits |  |  |
| 1. Turned down an opportunity for career advancement requiring a move to another state due to concerns about portability of Medicaid benefits across state lines |  |  |
| 1. Gave up working entirely |  |  |
| 1. Retired early |  |  |
| 1. Received a warning about your performance or attendance at work |  |  |
| 1. Other, please specify: | | |

1. How would you describe your own health?
   * a. Excellent
   * b. Very good
   * c. Good
   * d. Fair
   * e. Poor
2. How would you say taking care of the person with IDD has affected your health?
   * a. Made it better
   * b. Not affected
   * c. Made it worse
3. On average, how would you describe your stress level?
   * a. Not stressed
   * b. Somewhat stressed
   * c. Very stressed
   * d. Extremely stressed
4. How would you say taking care of the person with IDD has affected your stress level?
   * a. Lowered my stress level
   * b. Not affected my stress level
   * c. Raised my stress level
5. Below are some ways that people are proposing to help caregivers financially. Please rate the helpfulness of each.

|  |  |  |  |
| --- | --- | --- | --- |
| **Proposal** | **Not helpful** | **Helpful** | **Very Helpful** |
| 1. An income tax credit or deduction to caregivers to offset the cost of care |  |  |  |
| 1. A partially paid leave of absence from work for caregivers who are employed |  |  |  |
| 1. A program where caregivers could be paid for at least some of the hours they provide support |  |  |  |
| 1. An employee assistance program that provides case management services |  |  |  |
| 1. Help navigating the special education or adult services system as a benefit provided by employers |  |  |  |

1. Below are non-financial ways to help caregivers. Please rate the helpfulness of each.

|  |  |  |  |
| --- | --- | --- | --- |
| **Proposal** | **Not helpful** | **Helpful** | **Very Helpful** |
| 1. Providing on-line forums for caregivers to connect and help each other |  |  |  |
| 1. Providing “in-person” opportunities for caregivers to connect and help each other |  |  |  |
| 1. Providing on-line training in topics that are important to caregivers |  |  |  |
| 1. Providing face-to-face training in topics that are important to caregivers |  |  |  |
| 1. Providing better ways to bring concerns to policy-makers and legislators |  |  |  |
| 1. Providing caregivers with the ability to design and pay for individualized support rather than fitting into an existing program |  |  |  |

1. Which care giver topics, skills, or activities would you like to know more about or receive more assistance with to help you in your role as a caregiver?
2. Do you have additional ideas or suggestions on resources, programs, policies, or activities that would help you in your role as a caregiver?

Do you have a story related to caregiver experiences, rewards, challenges or solutions that you would like to share publicly? The Arc would love to hear from you as these stories can be used to inform our legislators on key disability issues that affect us all. Please send your story along with your name and contact information to [info@thearc.org](mailto:info@thearc.org) and use the subject header; “FINDS Story.”

**Thank you for completing our survey! We plan to use this important information to better develop programs and services that meet the needs of individuals and families across the lifespan. For more information about The Arc, please visit our website at www.thearc.org.**

**Please mail your completed survey to:**

**Lynda Anderson**

**University of Minnesota**

**210 Pattee Hall**

**150 Pillsbury Drive SE**

**Minneapolis, MN 55455**