



Caregiving and Planning for the Future for People with Disabilities

One of the great challenges facing today's caregivers for people with intellectual and developmental disabilities (I/DD) is balancing the responsibility of meeting their loved one's present needs with establishing a plan to ensure their continued care and supports in the future. The daily demands of caregiving for individuals with I/DD can be challenging, and commitment of time and resources that goes into ensuring a loved one's well-being leaves little time for much else, let alone planning for sustained supports and services in the future.

And yet, the need for future planning for caregivers and family members of individuals with I/DD is more dire than ever. As local and state agencies struggle to meet the growing demand for publicly-funded support services, it is imperative that caregivers develop a strategy to ensure that the individuals they support receive the proper care in years to come. This is especially true for the large national population of aging caregivers - there are an estimated 900,000 caregivers around the country over 60 years old, many of whom are the sole caregiver for their loved ones.

Shedding Light on the Issue: The 2017 FINDS Survey

In order to fully understand the many issues faced by caregivers across the country, The Arc of the United States and the University of Minnesota conducted the Family and Individual Needs for Disability Supports (FINDS) survey. More than 3,000 individual caregivers completed the survey, the results of which reveal a national community of family members and friends who are already stretched thin by current caregiving duties and who have little to no plans for how to support their loved one in the future.

On average, caregivers spend more than 57 hours a week caring for an individual with disabilities, which equates to more than 8 hours a day. More than 94% feel stress as a result of their caregiving and more than half of all survey individuals reported having issues with completing basic household tasks and chores (51%). Perhaps most alarming is that the majority of respondents (54%) do not have a plan for how to keep up their loved one's care in the future. This, added to the fact that the majority of caregivers (60%) have trouble finding specialists, managing benefits and communicating with other support professionals, paints a troubling picture of a caregiving population which is struggling to keep up with today's needs and is unprepared for tomorrow's challenges.

How The Arc Can Help - The Arc of the United States' Center for Future Planning is an invaluable resource for caregivers which aims to support and encourage adults with I/DD and their families to plan for the future. The Center provides reliable information and assistance to individuals with I/DD, their family members and friends, professionals who support them and other members of the community on areas such as person-centered planning, decision-making, housing options, and financial planning. It provides a suite of tools and resources dedicated to future planning, such as:



Build Your Plan® is a tool that enables families to create accounts and begin to build their plans within the Center. Always keep the person with I/DD's interests, preferences, and skills as the main focus of the plan.



CFP Video Library which contains videos of self-advocates explaining how to plan for the future in key topic areas like support services, housing, employment and others.



Training programs led by The Arc of the United States and local chapters help chapter staff, direct support providers and family members learn how to plan for the future.

Learn more by visiting futureplanning.thearc.org



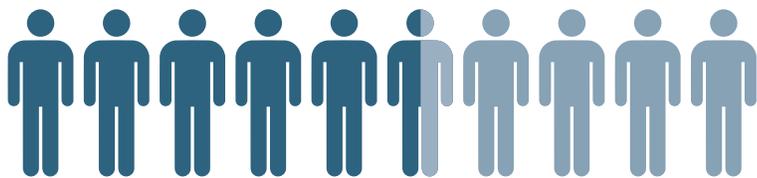
2017 FINDS SURVEY

Employment of People with Intellectual and Developmental Disabilities

About the FINDS Survey

The intent of this one-of-a-kind survey conducted by The University of Minnesota’s Institute on Community Integration in collaboration with The Arc is to understand the experiences of families who provide supports to a family member with intellectual or other developmental disabilities (I/DD). This is the second FINDS Report that The Arc has released; the first was conducted in 2010, and released in 2011.

Snapshot of Caregiving from The FINDS Survey

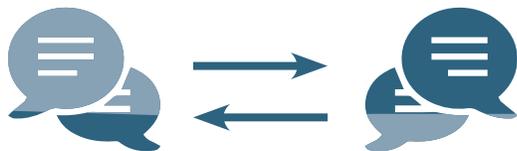


The majority of caregivers (54%) do not have a plan for how to keep up their loved one’s care in the future.

Family members and friends reported spending an average of 57 hours each week assisting loved ones



57
HOURS



(60%) have trouble finding specialists, managing benefits and communicating with other support professionals

95% of caregivers said they were stressed with nearly half describing themselves as very or extremely stressed.



The FINDS survey was implemented primarily using an on-line survey between January and March of 2017. Caregivers who were family members or friends of people with I/DD and who provided support were invited to participate in this survey.

More than 3,000 people (3,398) met the criteria to be included in the survey and consented to participate. Caregivers were surveyed including respondents from all 50 states, DC, Puerto Rico, and Guam. The number of people responding was large and provides important information about the experiences and outcomes of family caregivers of individuals with I/DD in the United States. However, the sample is not reflective of the racial and economic diversity of the United States.

