



# RESEARCH BRIEF

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## Support Services for Adult SSI Recipients with IDD

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### Overview



In 2017, the Research and Training Center on Community Living (RTC/CL) at the University of Minnesota and The Arc of the United States (The Arc) conducted an online survey, the *Family and Individual Needs for Disability Supports (FINDS)* survey. The purpose of *FINDS* is to better understand the experiences of families who provide supports to a family member with intellectual and/or developmental disabilities (IDD). Over half (52.6%) of non-elderly adults with IDD about whom caregivers reported in the *FINDS* survey received Supplemental Security Income (SSI). This databrief describes the characteristics and circumstances of these adult SSI recipients with IDD and the families who care for them.

### Background



The SSI program, operated by the Social Security Administration (SSA), provides a basic standard of living to approximately 6 million children and non-elderly adults with disabilities (SSA, 2018). To qualify, individuals must have extremely low incomes and limited savings, and must also meet Social Security's stringent disability standard. Most applications are

denied; ultimately, only about one-third of applicants for SSI are found eligible (SSA, 2017). SSI benefits average only about \$550 per month in 2018 (SSA, 2018), but this modest assistance plays a vital role in reducing extreme poverty and helping recipients to secure essentials such as food and housing (Center on Budget and Policy Priorities, 2017).

According to SSA, approximately 17% of SSI recipients age 18 to 64, and 9.7% of SSI recipients under age 18, have a primary diagnosis of intellectual disability (SSA, 2017). Rates of intellectual disability are even higher among SSI recipients when taking into account secondary diagnoses listed in SSA's administrative files (Livermore, Bardos, & Katz, 2017). While SSA does not collect data on "developmental disabilities," the agency classifies SSI recipients into several diagnostic groups that may be associated with developmental disabilities (such as "developmental disorders") (SSA, 2017).<sup>1</sup>

In 2017, the RTC/CL and The Arc conducted a national Internet survey that aimed to capture the experiences of family caregivers of people with IDD. Nearly 3,400 caregivers from every state, the District of Columbia, Puerto Rico, and Guam participated. The number of people responding was large and provides important information about the experiences and outcomes of family caregivers of individuals with IDD in the United States (U.S.). However, FINDS is an online convenience survey and the sample is not reflective of the racial and economic diversity of the nation. Because SSI is an income support program, this databrief analyzes an income-matched subsample of 1,225 FINDS respondents to better reflect household incomes of the U.S. This subsample was chosen based on the proportion of households at each income level reported by the United States Census Bureau at [factfinder.census.gov](http://factfinder.census.gov).

Of the *FINDS* income-matched sample, 565 or 52.6% respondents reported that the individual with IDD for whom they cared received SSI. Responses for one age group of SSI recipients with IDD were considered: adults aged 18 to 64 (N=498). Among other questions, family caregivers were asked about their backgrounds, employment status of the individual with IDD, and the types of supports and services provided to and received by the individual with IDD. With this databrief, the *FINDS* survey adds to the relatively limited body of literature on the characteristics, employment, and support needs of adults with IDD who receive SSI (Emerson, Felce, & Stancliff, 2013).

## Findings



**Demographics.** On average, non-elderly adults with IDD who received SSI were 28.9 years old, predominantly male (60.0% male, 40.0% female) and white (86.0%). 37.0% had ID, 17.6% had Autism Spectrum Disorder (ASD), 29.9% had ID and ASD, and 15.5% had other developmental DD (neither ID nor ASD). *FINDS* respondents providing support to this group of non-elderly adult SSI recipients were overwhelming female (90.4%) and parents (93.9%) to the adult with IDD. On average, family caregivers were 53.9 years old and predominantly white (90.9%). Three-fourths (74,870) lived with their family member. As noted above, this sample of *FINDS* respondents was constructed to reflect the U.S. family income distribution (accounting for family size). Because survey respondents were convenience sampled over the Internet, they were not representative of the U.S. population, and therefore their demographics, experiences, and circumstances may not be representative of the general population of family caregivers or individuals with IDD in the U.S.

*Table 1: Top 3 examples of each type of support provided*

Type of Support	Percent Providing Support
<b>ADL</b>	
Assists with hygiene/grooming	72%
Assists with dressing/undressing	56%
Assists with toileting	46%
<b>IADL</b>	
Transportation support	95%
Supports advocacy/self-advocacy	93%
Assists with errands, shopping, etc	88%
<b>Health Supports</b>	
Communicating with health care providers	96%
Finding and coordinating specialists	91%
Following up with therapies and treatments at home	46%
<b>System and Service Supports</b>	
Monitoring progress	92%
Arranging social and leisure activities	90%
Obtaining day activities	79%

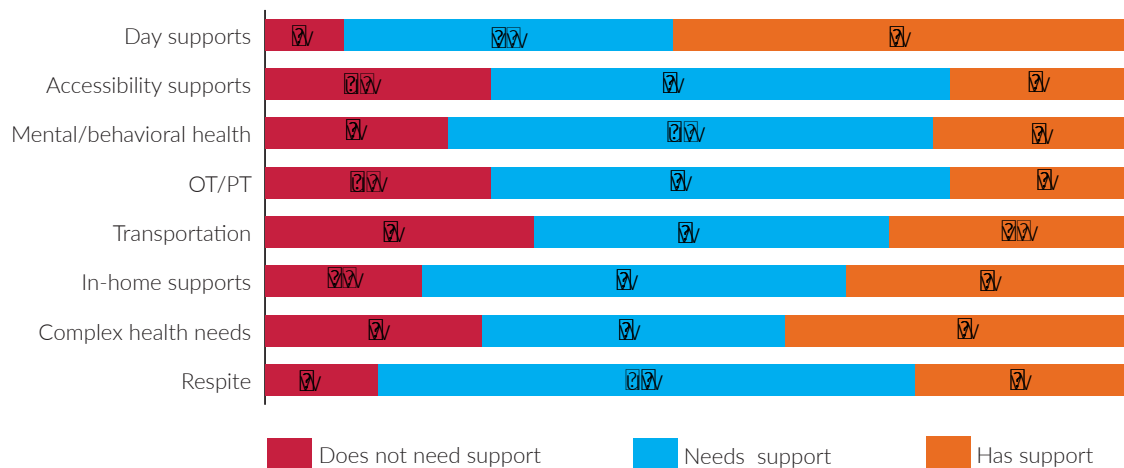
**Supports and services.** Survey participants spend significant time providing support to their adult family member with IDD: 58.8% report spending over 80 hours per week, 21.0% report spending 41 to 80 hours per week, 6.1% report spending 31 to 40 hours per week, 6.6% report spending 10 to 30 hours per week, and 17.1% report spending 9 or fewer hours per week.

Survey participants reported that on average they support the adult with IDD with 2.9 Activities of Daily Living (ADLs), 8.7 Instrumental Activities of Daily Living (IADLs), 2.3 health supports, and 7.6 service and system supports.<sup>2</sup> These numbers reflect supports provided directly by survey respondents and do not include supports provided by others, such as direct support professionals. For example, nearly half (49.3%) of survey participants reported that the adult with IDD receives in-home supports (people come to the home to assist the adult with IDD). 60.9% of survey respondents reported that the SSI recipient with IDD has a court-appointed legal guardian.

Across multiple areas, family caregivers described significant yet unmet needs for the adult with IDD to access more supports and services (see Figure 1). For example, 67.0% reported that their adult family member with IDD has unmet needs for day supports, 52.6% reported unmet needs for accessibility supports, 52.0% reported unmet needs for

mental/behavioral health care or other therapies such as physical or occupational therapy, 49.6% reported unmet needs for transportation (to go to work or a day program, medical visits, etc.), 48.5% reported unmet needs for in-home supports, and 33.8% reported unmet needs for assistance with complex health needs. In addition, 57.7% of family caregivers reported unmet needs for respite care, or periodic supports and services provided to a person with a disability to give a caregiver short-term relief (Edgar & Uhl, 2011). In each area, unmet needs include adults with IDD who receive some supports, but need more, as well as adults with IDD who receive no supports at all in that area, but support is needed.

**Figure 1: Met and Unmet Needs**



Nearly half of respondents, or 48.5%, reported that the support services in their community are decreasing. Another 43.1% reported that supports are staying about the same, while 8.4% reported that supports are increasing.

50.4% of respondents lack a plan that identifies who will support the person with IDD, if they are no longer to do so. When asked to imagine a future when they may not be able to support the person with IDD, 79.7% indicated that there is no one else to provide the support that they currently offer, and 90.4% believe that the quality of support will go down if they are not there to advocate in support of the person with IDD.

**Employment.** Survey participants were asked if the adult with IDD had a paid job, as well as the hourly rate, job supports, and type of job (competitive integrated employment or

**Figure 2: Employment Supports Received**



not competitive integrated employment). 29.1% of adults with IDD had a paid job with an average income of \$7.87 per hour, or just slightly above the federal minimum wage rate of \$7.25 per hour. The average number of hours worked in a two week pay period was 25.3. Nearly half reported that the adult with IDD (48.6%) receives individual employment support, while 21.8% reported no employment supports. Roughly one-fifth (21.1%) of adults with IDD had competitive integrated employment – generally understood to mean work in the community alongside workers without disabilities, earning at least minimum wage, with wages and benefits similar to colleagues without disabilities in comparable jobs (Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities, 2016). Nearly half (48.6%) of all respondents saw a need for the adult with IDD to be able to access more competitive integrated employment.

## Summary & Discussion



Consistent with other research, the *FINDS* survey highlights that SSI recipients with IDD on average require significant levels of supports across a wide range of activities. The overwhelming majority of caregivers, or 8 in 10 respondents, provide 40 or more hours per week providing supports to their family member with IDD. Compared to caregivers across the nation, *FINDS* respondents – including those with an adult family member who receives SSI – spend on average more time providing support across a greater number of activities. For example, in *Caregiving in the U.S. 2015*, caregivers spent an average of 24.4 hours per week providing care (AARP Public Policy Institute & National Alliance for Caregiving, 2015).

*FINDS* survey respondents also report that SSI recipients with IDD face major unmet needs for services such as accessibility and employment supports, transportation, in-home supports, specialized therapies, and medical services. Alarming, nearly half of *FINDS* respondents indicate that the support services in their community available to the adult SSI recipient with IDD are decreasing. Major reported gaps in supports, services, and accommodations emphasize the need for additional in-home and community supports to enable these adults to reach their full potential at home, school, and in the community.



## Endnotes



- <sup>1</sup> “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*, published by the American Psychiatric Association (APA, 2013). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the *Developmental Disabilities Assistance and Bill of Rights Act 2000*. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.
- <sup>2</sup> ADLs include helping getting in and out of bed/chairs, getting dressed/undressed, getting to and from the toilet, bathing/showering/grooming, providing post-toileting/hygiene/diapers, assisting with eating, and supporting the person with mobility (walking, standing, wheelchair). IADLs include giving medications, making decisions about everyday matters (e.g., what to wear to when to go to bed), managing finances (e.g., banking, paying bills, or filling out forms), doing errands or grocery/other shopping, doing simple home upkeep (e.g., doing dishes, laundry, straightening up or changing bulbs and tightening screws), preparing simple meals or arranging for meals, providing transportation or arranging for rides, providing advocacy or supporting self-advocacy, and organizing/prioritizing tasks. Health supports included following up with OT/PT/treatments at home, finding specialists and coordinating those services, communicating with support and health care professionals about progress and needs, and performing medical tasks (e.g., feeding with a tube, suctioning, and monitoring respiration). Service & system supports included support with employment/career/educational support (e.g., finding and keeping a job, volunteering), obtaining day activities (e.g., recreational programs), finding personal care assistants/aides/DSPs finding respite services to enable the person with IDD and the caregiver to have some time apart, supporting with child or after school care (if the person is under 18 years), noting progress and making changes if needed, arranging for federal or state entitlements (benefits) or managing entitlements (e.g., social security), obtaining person-centered planning and support, arranging social and leisure activities, providing direct financial support, and helping with self-directing services (e.g., supervising and paying wages to in-home workers).

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