



FINDS

Family & Individual Needs
for Disability Supports

Community Report 2017

FINDS Family & Individual Needs for Disability Supports Community Report 2017

Suggested Citation

Anderson, L*, Hewitt, A*, Pettingell, S*, Lulinski, A**, Taylor, M***, & Reagan, J*. (2018) Family and Individual Needs for Disability Supports (v.2) Community Report 2017. Minnesota: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

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

** Coleman Institute for Cognitive Disabilities, University of Colorado

*** Consultant, LittleWing

This project is funded through a grant 90RT5019 from the U.S. Department of Health and Human Services, Administration on Community Living, National Institute on Disability and Independent Living Rehabilitation Research and grant 90DN0297 from the U.S. Department of Health and Human Services, Administration on Community Living, Administration on Intellectual and Developmental Disabilities. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not therefore necessarily represent official ACL or NIDILRR policy.

About FINDS

An estimated 7.3 million people with intellectual or other developmental disabilities (IDD) live in the United States (Larson, et al, 2018). About 1.2 million of these individuals receive formal supports through their state's Developmental Disability agency (Larson, et al 2018). Formal supports may include Medicaid Home and Community Based Services (also known as "waivers") that provide in-home, residential, employment, or other supports that enable persons to live in the community. More than half (53%) of people with IDD receiving a Medicaid-funded service live with their family (Larson, et al, 2018). This means that families play an important role in providing care to their family members with IDD. Supports provided vary widely and include interventions to support people in areas of behavior, health and medical supports (such as therapies), transportation, assistive technologies, and assistance with daily living activities such as preparing meals, personal care, shopping, etc.

The *Family and Individual Needs for Disability Supports (FINDS)* survey was initially conducted by The Arc of the United States in 2010. It was updated in 2017 through a collaboration between the Research and Training Center on Community Living (RTC/CL) at the University of Minnesota and The Arc. The purpose of *FINDS* is to understand the experiences of families who provide supports to a family member with IDD. An estimated 43.5 million people provide support to a family member who is aging or who has a disability (National Alliance for Caregiving, 2015). Important questions exist about families who provide such support:

1. What are the challenges families face meeting the support needs of their family member?
2. What are the economic implications of caregiving?
3. How does caregiving affect caregivers and what supports do they need?

Better understanding the experiences and needs of caregivers can help policy makers and other support caregivers in this important role.

How we conducted the survey

The *FINDS* survey was primarily an on-line survey administered between January to April of 2017. The survey was also made available in English and Spanish paper versions. Caregivers who were family members or friends of people with IDD and who provided support were invited to participate in this survey. Direct support professionals or other caregivers whose primary relationship with individuals with IDD was in a paid role were not included in the sample.

More than 3,000 people (3,398) met the criteria to be included in the survey and consented to participate. Individuals from every state, the District of Columbia, Puerto Rico and Guam participated.

Other family caregiver surveys

Caregivers of individuals with IDD may have different experiences than caregivers who provide supports to other groups of people. For example, caregivers of individuals with IDD usually provide supports over the lifespan of their family member rather than during specific stages of life (e.g., when elderly or post injury). To better understand how the experiences of caregivers of individuals with IDD may be similar or different from other caregivers, comparison questions were selected from other surveys.

The Caregiving in the U.S. 2015 survey was conducted by the National Alliance on Caregiving and AARP with the goal of describing the experience of unpaid caregivers. This survey was conducted on-line and included 1,248 caregivers from across the United States providing supports to aging relatives or family members with disabilities. The *Caregiving in the U.S.* survey had small sample sizes of some ethnic sub-groups of the population and, therefore, may not be a representative sample.

National Core Indicators - Adult Family Survey and/or a Child Family Survey (NCI) was also used. *NCI* is a program implemented through a collaboration between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) designed to measure performance

and outcomes for developmental disabilities (DD) service and support systems. Many states (but not all) participating in *NCI* field an Adult Family Survey and/or a Child Family Survey for caregivers of adults or children living in the family home and receiving Medicaid-funded supports and services. *NCI* family surveys are only sent to families of individuals receiving waiver-funded supports and services through their state’s DD agency, and, therefore, may not be representative of the population as a whole.

Reflecting the diversity of the U.S.

Due to the limited number of caregivers who identified as Asian, African-American, American Indian or Alaska Native or some other background, any comparisons by race are comparing individuals identifying as white with people who identified as some other race or ethnicity. Difference across income were examined by comparing individuals who reported being above or below the U.S. median household income (\$59,000). When caregiver responses differed between income groups or race, the differences are noted in each section. In many areas, caregivers of different backgrounds reported similar experiences, so differences by income group or race are not discussed in those sections.

Caregivers description

Table 1 shows the characteristics of caregivers responding to the *FINDS* survey compared to caregivers who participated in the *Caregiving in the U.S.* survey and the *NCI*. Most of the caregivers responding to the *FINDS* survey were female (89%). Among caregivers identifying as something other than white, 16% were male compared to white caregivers (11%). The *Caregiving in the U.S.* 2015 survey reports a higher percentage of male caregivers (40%). The difference may be related to the relationship between the caregiver and the family member. While *FINDS* survey Caregivers are primarily parents (87%), only 5% of *Caregiving in the U.S.* Caregivers were parents (NAC, 2015). In the U.S., women generally are in the primary caregiver role for children (Heller, 1997; Yavorsky, et al, 2015).

Table 1: Characteristics of Caregivers in the *FINDS* and *Caregiving in the US*

	FINDS	Caregiving in the U.S.	National Core Indicators
Gender (N=3,169)			
Male	11%	40%	
Female	89%	60%	
Age (N=3,161)			
18-34	5%	24%	13%
35-54			59%
35-49	28%	23%	
50-64	50%	34%	
55-74			25%
65-74	15%	12%	
75+	2%	7%	3%
Race (N=3,125)			
White	89%	53%	39%
Black	4%	16%	11%
Latino	3%	16%	33%
Other	2%		6%
Two or more	2%		
Asian		15%	11%
Relationship to family member (n=2,905)			
Parent (adult child)	60%	5%	
Parent (child)	27%		66%
Sibling	6%	5%	2%
Child	*	49%	
Spouse	*	12%	
Other relative	3%	14%	3%
Non-relative	3%	15%	
Lives with family member (n=2,923)			
	80%	35%	100%

* less than 1%

Table 2: Characteristics of Family Members with Disability

	FINDS	Caregiving in the U.S.	National Core Indicators
Gender (N=2,936)			
Male	63%	35%	68%
Female	37%	65%	32%
Age (N=3,398)			
0-5	4%		
6-13	17%		
14-21	23%		
18-49		14%	
22-40	44%		
41-64	11%		
50-74		39%	
65+	1%		
75+		47%	
Race (N=2,860)			
White	83%		
Black	4%		
Latino	2%		
Other	5%		
Two or more	7%		
Disability (N=2,935)			
ID	34%		
ASD	25%		
ID/ASD	24%		
Other	17%		
"Old age"		14%	
Alzheimer/ Confusion		8%	
Mental Health		5%	
Physical Disability/ Illness		53%	

The racial/ethnic background of the *FINDS* Caregivers is less diverse than that of the *Caregiving in the U.S.* survey. Different ways of recruiting people to participate likely explain these differences. The background of *FINDS* Caregivers is 89% Caucasian/White, 4% Black/African American, 3% Latino; 2% Other, and 2% two or more races. The *Caregiving in the U.S.* survey reported that their Caregivers were 53% white, 16% black, 16% Latino, and 15% Asian.

The *FINDS* Caregivers had an average age of 54. White Caregivers were more likely to report being 65 and older (18%) and less likely to be 49 and younger (31%) than Caregivers from other backgrounds (14%; 45%). Two-thirds (67%) of *FINDS* Caregivers were 50 or older. The Caregivers in the *Caregiving in the U.S.* survey were younger, with slightly more than half (53%) 50 years or older.

One of the biggest differences between *FINDS* Caregivers and Caregivers in the *Caregiving in the U.S.* survey was the relationship of caregivers to their family member. Most caregivers (79.4%) lived with their family member with IDD. More than half reported (56.8%) provided support to an adult family member, 27% to a child, and 16% cared for an adult and child with IDD. Caregivers were generally parents (87%) followed by siblings (6%). The remaining caregivers (7%) were other family members or friends. Only 5% of Caregivers in the U.S. survey were parents, the majority were children (49%), followed by spouses (12%). *FINDS* Caregivers identifying as white were somewhat more likely to be parents (87%) than caregivers of other backgrounds (83%).

FINDS caregivers reported providing supports to their family member for longer than caregivers responding to the *Caregiving in the U.S.* survey. About 1/5 (19%) reported having been providing support to their family member for fewer than ten years. More than a third (35%) having been providing supports for more than 25 years. The *Caregiving in the U.S.* study found that 24% of caregivers had been provided support for 5 or more years. Thirty percent of Caregivers in *Caregiving in the U.S.* had been providing care for less than a year. Only 12% reported providing

this support for more than 10 years. This difference highlights the lifelong role of caregiver for family members of individuals with IDD. According to the *Caregiving in the U.S.* report (2015), 1 in 10 caregivers is 75 years of age or older highlighting the caregiving crisis. As the general population of caregivers continues to age, younger generations have and will continue to assume major caregiving roles.

Family member description

As indicated in Table 2, family members with disabilities ranged in age from 0-89, with an average age of 25. Most were between the ages of 22 and 40 (44%). Most family members were also male (63%). Families reported that 83% of individuals being supported were White/Caucasian, 4% Black/African American, 2% Latino, 5% Other, and 6% reported as two or more races.

One-fourth of caregivers reported that their family member had both intellectual disability (ID) and autism spectrum disorder (ASD) (24%); 25% had ASD, but no ID; 34% had ID, but no ASD; and, 17% had other diagnoses but not ID or ASD. The 2017 respondents were more likely to identify ASD than they were in the 2010 *FINDS*. One-third of 2010 *FINDS* caregivers (34%) indicated that their family member had ASD, with or without ID. The identified disability of the family member differed by race. *FINDS* Caregivers other than white were more likely to report their family member had ASD without ID than

Nearly 2/3 of the caregivers work in addition to their caregiving duties.

those who were white (32% versus 24%). Conversely, those who were white were more likely to report that their family member had ID without ASD (35% versus 26%).

Caregiver Experiences and Outcomes

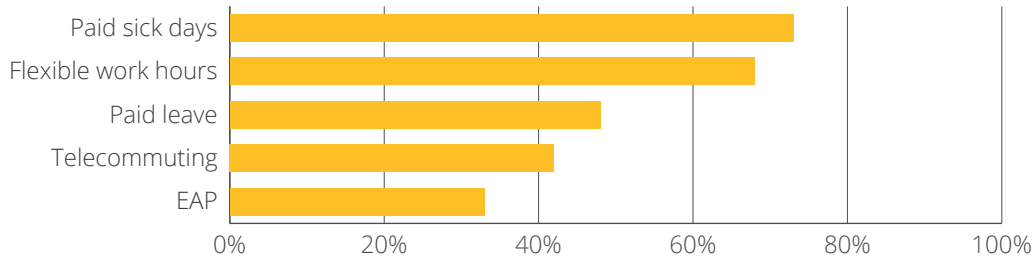
Caregivers work outside of providing support to their family member

Nearly 2/3 of caregivers reported working in addition to their caregiving responsibilities. Most were employed by someone else (53%). African-American parents were more likely than the average to report working outside of the family home (60%) as were caregivers of family members with other developmental disabilities (56%). Mothers and fathers were about as equally likely to report working, however women were more likely than men (53% vs 50%) to be employed by someone else while more fathers reported being self-employed (12% vs 10%). Of those caregivers that report working, more than half (55%) work more than 40 hours per week.

Benefits offered by employer

Most of the caregivers who worked reported that their employers offered paid sick days (73%) and flexible work hours (68%). Less than half of *FINDS* caregivers reported having paid leave (48%), the ability to telecommute (42%) or being able to access employee assistance programs (33%). Caregivers in the *FINDS* survey reported higher availability of these types of benefits than did caregivers in the *Caregiving in the U.S.* survey (NAC, 2015). Caregivers reported receiving the following benefits: flexible work hours, 53%; paid sick days, 52%; paid family leave, 32%; programs to help caregivers (such as employee assistance programs), 23% and telecommuting, 22%. The median income for *FINDS* caregivers was higher than that of the general population and the *Caregiving in the U.S.* survey, which may explain the difference in employer benefits.

Benefits offered by employer



Work outcomes related to caregiving

Almost all working *FINDS* Caregivers (95%) report that caregiving has had some impact on their work. Six in ten Caregivers (61%) report experiencing three or more of the following work impacts from caregiving:

Work time and workforce participation

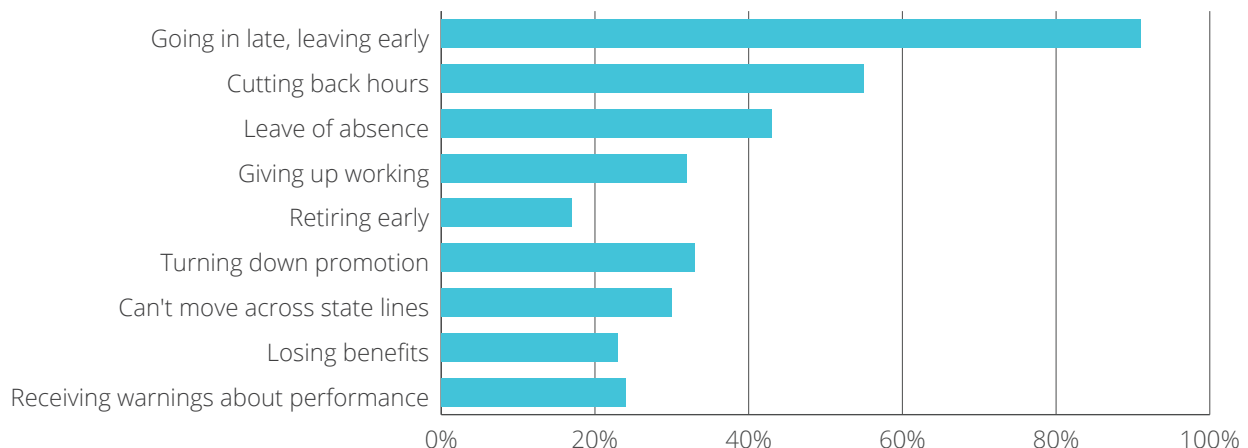
- going in to work late, leaving early or taking time off during the day to provide care (91%),
- cutting back their hours (55%),
- taking a leave of absence (43%),
- giving up work entirely (32%),
- retiring early (17%),

Advancement and benefits

- turning down a promotion (33%),
- turning down career opportunities in other states due to the lack of Medicaid portability across state lines (30%),
- losing benefits (23%), or
- receiving warnings about work attendance or performance (24%).

FINDS Caregivers identifying as white were less likely to report taking a leave of absence (42%) or receiving a warning about work performance/attendance (24%) than other caregivers (51%; 33%). The employment effects of caregiving differed by household income. Those caregivers with household incomes of less than \$59,000 were more likely to taking a leave of absence (47% versus 41%); reducing hours from full to part-time (60% versus 52%) report losing benefits (31% versus 19%), giving up working (35% versus 30%), or receiving warnings about attendance or performance (35% versus 19%) than caregivers with household incomes above \$59,000.

Work outcomes related to caregiving



Almost all FINDS participants that work report that caregiving has had some impact on their work.

Caregivers in the *Caregiving in the U.S.* survey were less likely to report negative impacts on work than did *FINDS* Caregivers. Roughly half of the *Caregiving in the U.S.* Caregivers reported going in late, leaving work early or taking time off (49%). Other impacts reported in the *Caregiving in the U.S.* survey included talking a leave of absence (15%), reducing work hours or taking a less demanding job (15%), receiving a warning about attendance or performance (7%), giving up work entirely (6%), turning down a promotion (5%), retiring early (4%) or losing benefits (3%).

Caregiver's perspectives on what helps

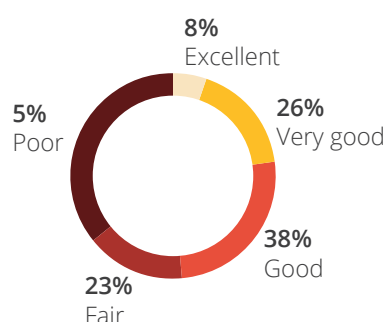
FINDS Caregivers were asked to identify the top three things their employers could do to that would be helpful in balancing their work and family responsibilities. Caregivers identified the following as most important:

- supportive and understanding supervisors and co-workers,
- flexible scheduling and flexible use of paid time off – either informal or formal, and
- benefits such as medical or dental insurance and flexible spending accounts.

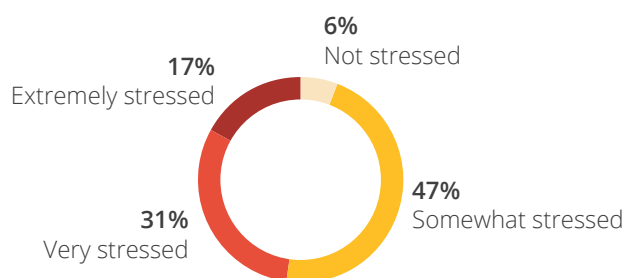
Caregiver health status

Most *FINDS* respondents reported that their own health was good (38%) or very good/excellent (34%). This is somewhat lower than the *Caregiving in the U.S.* survey in which 48% of the caregivers reported that their health was very good or excellent. *FINDS* Caregivers were more likely than *Caregiving in the U.S.* survey to report fair (23% vs 15%) or poor health (5% vs 2%).

Caregiver health status



Caregiver stress level



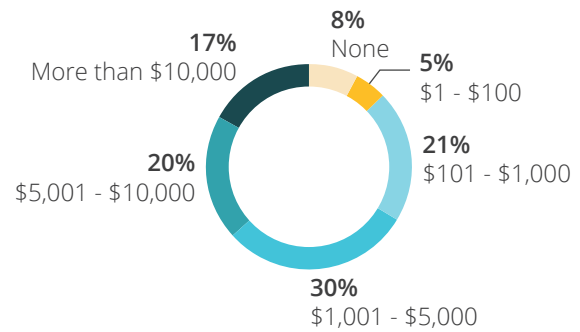
Caregiver stress level

Nine in ten *FINDS* Caregivers reported that they were stressed. Nearly half reported being somewhat stressed (47%). Another 48% reported being very or extremely stressed. The number of caregivers reporting that they were very or extremely stressed has increased since the *FINDS* 2010 survey in which 42% of caregivers reported being very or extremely stressed. Caregivers in the *Caregiving in the U.S.* survey were much less likely to report that caregiving related stress (84%).

Out of pocket expenses for care

Roughly nine of 10 *FINDS* Caregivers reported some out-of-pocket expenses related to their family member's disability (92%). Two-thirds (67%) reported expenses of \$1,000 or more per year. One-third (36%) reported expenses totaling \$5,000 or more per year. The number of families reporting any out-of-pocket expenditures has increased since the 2010 *FINDS* survey. The 2010 *FINDS* did not report amounts of expenditures, but only 47% of caregivers reported paying for services out-of-pocket; this represents a substantial increase. Caregivers responding to the *NCI* family surveys were somewhat more likely to report no out-of-pocket expenses (19%) and about 31% reported expenses totaling more than \$1,000 per year (Anderson, et al, 2016).

Out of pocket expenses

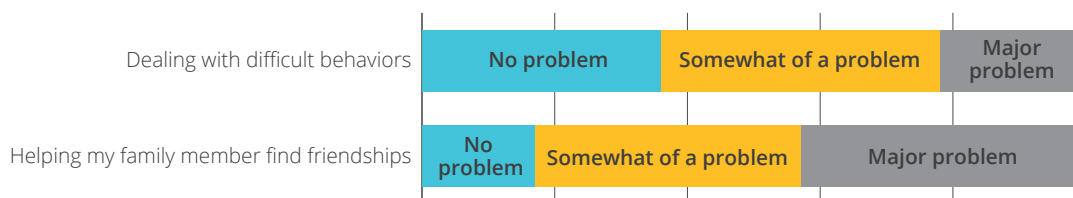


Caregiver responsibilities

FINDS Caregivers (85%) report that balancing responsibilities (e.g. children, work, marriage) is a challenge. Caregivers report difficulties addressing their own health issues (somewhat of a problem 44%; major problem 21%) and finding time to meet their personal needs (e.g. personal time, exercise, etc. -somewhat of a problem 37%, major problem 49%). The number of caregivers reporting difficulties finding time to meet their own needs has increased since the 2010 *FINDS* when 81% of caregivers having somewhat of a problem (40%) or a major problem (41%) finding time to meet their own needs.

More than half of all *FINDS* Caregivers reported dealing with dangerous or difficult behaviors of the person they support (64%) and supporting friendships and inclusive community experiences (83%) as challenges in meeting the needs of their family member with disabilities. These are similar to the challenges reported by Caregivers in the 2010 *FINDS*.

Caregiver responsibilities



Caregiver's top three identified supports

FINDS respondents were asked in an open-ended question to list their top three supports "that do, or might, help you to have a more positive outcome?" *FINDS* Caregivers overwhelmingly identified

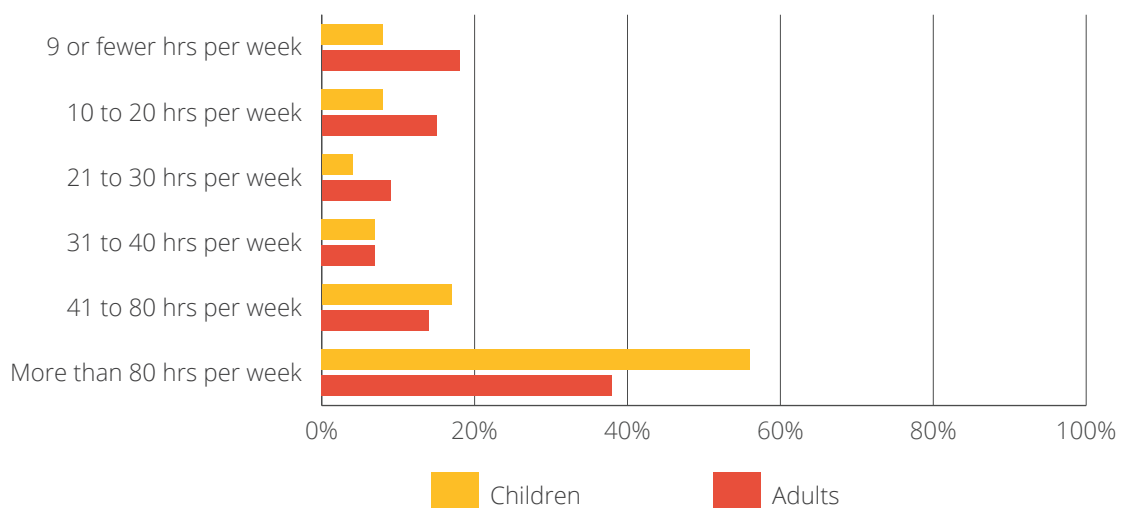
- Access to high-quality, affordable supports (e.g. day programs, employment supports, in-home supports, behavioral supports, health supports, respite, and long-term residential supports),
- Time for self-care activities and time for sleep,
- Stable long-term government funded support programs and financial supports/security.

Home and Community Supports

Hours of support provided by caregiver per week

FINDS Caregivers reported providing support to their family member an average of 57.4 hours per week. The average number of hours provided for care by *FINDS* Caregivers was more than twice the hours (24.4) that reported by Caregivers in the *Caregiving in the U.S.* study. Caregivers of children (74%) were more likely than caregivers of adults to report providing more than 40 hours of care per week (52%). This is an increase over the 2010 *FINDS* results in which 58% of caregivers of children and 59% of caregivers of adults reported providing care more than 40 hours per week. Few caregivers are providing paid support to their family member (only 15% are paid).

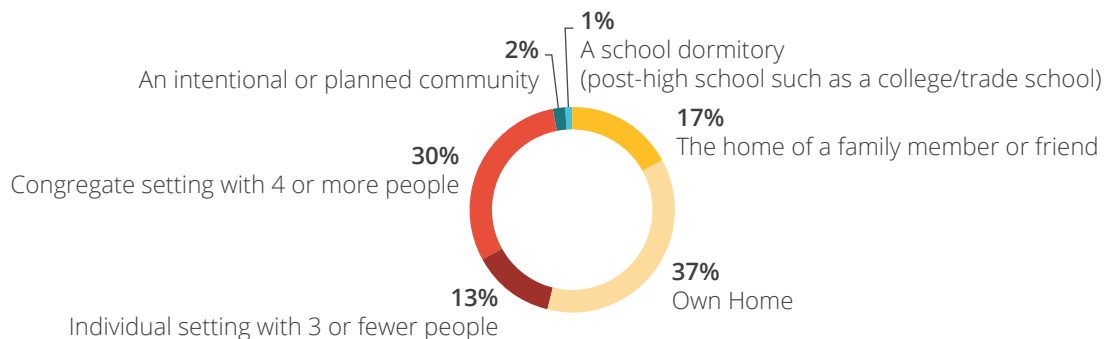
Hours of support provided by caregiver



Living arrangement of PWD

Most *FINDS* Caregivers (80%) report that their family member with disabilities lives with them. In the 2010 *FINDS*, 75% of caregivers reported that their family member lived with them. White *FINDS* Caregivers were less likely to report that they lived with their family member (79%) than other caregivers (86%), although white *FINDS* Caregivers tended to be older and less likely to be caring for children or young adults. Of those that do not live with their family, one-third (37%) lived in their own home and another 30% lived in a congregate setting with four or more people with IDD. The remaining third lived in a variety of living arrangements: with a friend or family member (17%), in a residential setting with three or fewer people with IDD (13%), in an intentional or planned community (2%) or in a college dormitory (1%).

Living arrangement for those living outside of home



Technology use

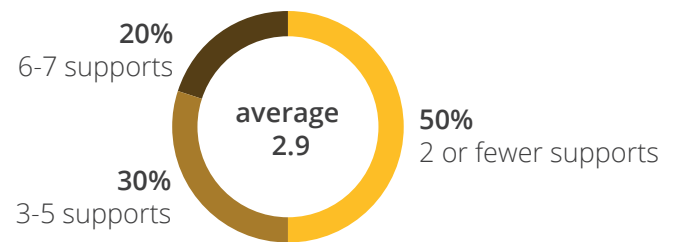
A majority of *FINDS* Caregivers reported that their family member had access to a tablet (68%), laptop or desktop computers (46%), video game consoles (45%), and smart phones (39%). Disability specific technology was identified as being used by fewer than 25% of caregivers. Smart home technology was used by 7% of family members with IDD and 21% used picture communication software/devices. Nine of ten of the caregivers reported that their family member with IDD had access to broadband internet at their residence (87%), reflecting the on-line nature of the *FINDS* survey. Three-fourths of the U.S. population reports having access to broadband internet (73%) (PEW, 2017). The general population is much more likely to report smartphone use (77%) and less likely to report owning a tablet (51%) (PEW, 2017).

Caregivers provide ADL supports

Activities of daily living (ADL) include toileting, eating, dressing, grooming and hygiene, and mobility which may include transfers, getting in and out of chairs or bed, and walking. An overwhelming majority of *FINDS* Caregivers (76%) reported that they provide support for at least one ADL for their family member. The mean number of ADL supports provided was 2.9 (out of seven). Half of *FINDS* Caregivers report providing two or fewer ADL supports (50%), 30% provide between three and five ADL supports, and the remaining 20% provide six to seven such supports. The Caregivers in the U.S. survey identified six ADL supports. Caregivers in this survey provided an average of 1.7 ADL supports with 59% providing at least one such support.

The amount of supports needed varied depending on the identified disabilities of the individuals needing supports. Individuals with both ID and ASD were reported to have the highest ADL support needs (85%), followed by individuals with ID (78%), individuals with other disabilities (70%) and individuals with ASD (67%).

Activities of daily living supports



FINDS caregivers (76%) reported that they provide support for at least one ADL for the person they support.

The amount of supports needed varied depending on the identified disabilities of the individuals needing supports. Individuals with both ID and ASD were reported to have the highest ADL support needs (85%), followed by individuals with ID (78%), individuals with other disabilities (70%) and individuals with ASD (67%).

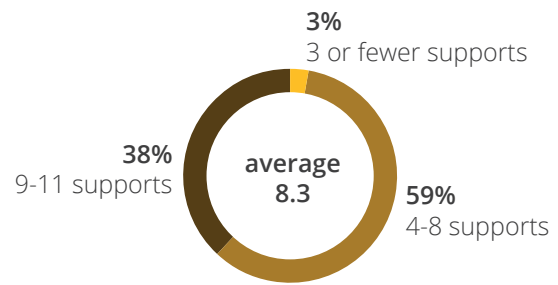
Caregiver provides IADL supports

The *FINDS* 2017 survey included 10 items under Instrumental Activities of Daily Living (IADL). IADL supports included:

- giving medications, making decisions about everyday matters (e.g., what to wear when to going to bed),

- managing finances (e.g., banking, paying bills, or filling out forms),
- doing errands or grocery/other shopping, completing simple home upkeep (e.g., doing dishes, laundry, straightening up, or changing bulbs and tightening screws),
- preparing meals or arranging for meals,
- providing transportation or arranging for rides,
- providing advocacy or supporting self-advocacy, and
- organizing/prioritizing tasks.

Instrumental Activities of Daily Living supports



Nearly all Caregivers in the *FINDS* survey (99.5%) reported providing support for at least one IADL. Only 3% of caregivers reported providing 2 or fewer of these kinds of supports. More than half (59%), provided between four and eight and a third (38%) reported providing between nine and 11 IADL supports. The average number of IADL supports provided was 8.3. This is similar to the *Caregiving in the U.S.* survey in which 99% of caregivers reported providing support for at least one IADL.

All caregivers (99.5%) reported providing support for at least one Instrumental Activity of Daily Living.

Caregiver provides health supports

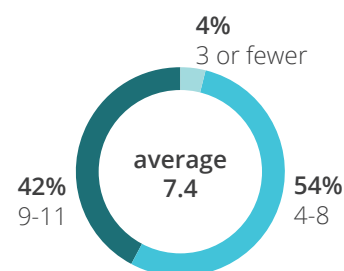
Health supports included assistance in obtaining Occupational Therapy/Physical Therapy/Other Treatments at home, finding specialists and coordinating those services, communicating with support and health care professionals about progress and needs, and performing medical tasks (e.g., feeding with a tube, suctioning, and monitoring respiration). Nearly all of *FINDS* Caregivers (97%) reported providing a health-related supports. More than half (58%) provided two or fewer health-related supports while the remaining 42% provided three or four supports. The average number of health supports was 2.3.

Caregiver provides service and system supports

Nearly all (99.4%) *FINDS* Caregivers reported providing at least one of the service and system supports identified in the *FINDS* survey. They provided an average of 7.4 such supports. The supports included:

- 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

Service and support systems



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).

More than half of *FINDS* Caregivers (59%) reported providing four to eight system related supports for their family member, while 38% reported providing between nine and 11. Only 8% reported providing three or fewer.

All (99.4%) caregivers reported providing at least one service and system support.

Caregiver provides behavior supports

Behavior supports include crisis prevention or intervention or on-going management of behavioral outbursts, aggression or self-injurious behavior. Seven of ten *FINDS* Caregivers reported that they provide some level of behavioral support for their family member (72%). Individuals with both ID and ASD (86%) were more likely to need behavioral support than were individuals with ID only (63%), ASD only (79%), or individuals with other disabilities (55%).

Family member supports are increasing/decreasing

Few caregivers reported that support services in their communities were increasing (8%). Almost half of the *FINDS* Caregivers reported that supports are decreasing (44%). Caregivers making less than \$59,000 per year were more likely to report that services in their community were decreasing (49%) than were households with higher incomes (40%). The number reporting that services decreasing is down from the 2010 *FINDS* (62%), which was fielded during the time period of the Great Recession. The number of caregivers reporting that services are staying the same has increased from 31% in the *FINDS* 2010 survey to 48% in 2017. The number of *FINDS* Caregivers reporting that community services are decreasing is much higher than the 26% of families in the *NCI* family surveys reporting that their services were reduced or suspended in the preceding year (Anderson, et al, 2016).

Top three supports

FINDS Caregivers identified the top three supports that they provided for the individual they support. Caregivers identified:

- Activities of daily living, including dressing, grooming, hygiene, feeding, and mobility,
- Financial — this ranged from ensuring paperwork was done to maintain benefits, assisting with paying bills and managing money, to direct financial support such as paying for services, housing, and other expenses, and
- Providing supervision and ensuring the safety of the person they supported.

One in five have been waiting for more than 10 years (20%), while 25% have been waiting for one year or less.

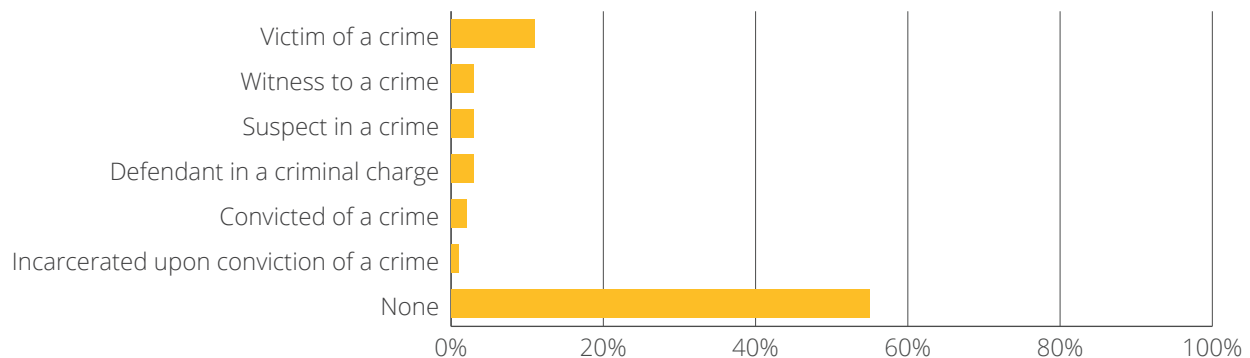
Family member is waiting for services

One in four (28%) reported that their family member was waiting for a government-funded services. Medicaid waivers were the most frequently mentioned support for which people were waiting. Households with incomes below the U.S. median income were less likely to report being on a waiting list for services (22%) than were those with higher household incomes (30%). One in five have been waiting for more than 10 years (20%), while 25% have been waiting for one year or less.

Family member has involvement in criminal justice system

Nearly half of caregivers (45%) reported that their family member had some involvement with the criminal justice system. One in ten of the family members with IDD supported had been a victim of a crime (11%) and another 3% have witnessed a crime. Caregivers reported that their family member had been a suspect in a crime (3%), been a defendant in a criminal case (3%), been convicted of a crime (2%), or been incarcerated upon conviction (1%). An additional 2% of *FINDS* Caregivers report that the person they support has had some other involvement with the judicial system.

Criminal justice system



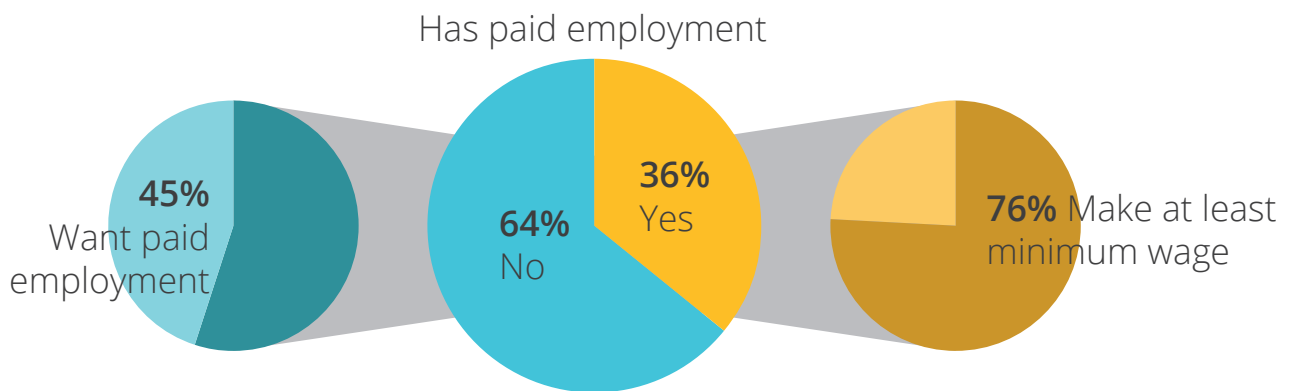
Work and Employment Supports

Person supported has paid employment

The following responses are for individuals supported who were 22 and older. One-third (36%) of the individuals supported had a paying job. This is a much higher rate of employment than that reported in the *National Core Indicator* surveys in which 15% of adults with IDD are reported to have community employment. Only 4% of those reported to be employed were competitively employed (Butterworth, et al, 2015). Of those with who had paid employment in the 2017 *FINDS*, 74% were paid at least minimum wage. Most caregivers (84.9%) reported that their family member was satisfied or very satisfied with their wages. White caregivers were more likely to report that their family member was employed (33%) than other caregivers (23%). Most of the individuals who had paid jobs were in integrated jobs in community settings (58%). Others worked in paid facility-based employment (24%), in group community-based employment (12%) or were self-employed (6%). Most of the people who were employed

received individual employment support (47%) or group employment support (21%). One in four people who were employed received no employment supports (22%). Relatively few individuals who were employed received employment benefits (18%). The levels of employment have increased since the 2010 *FINDS* when 15% of individuals supported were reported to have a job. Self-employment has also increased from 1% since the *FINDS* 2010 survey. In the 2010 *FINDS*, 48% of Caregivers reported that the individual supported received a “competitive wage.” Assuming this is at least minimum wage, this also shows an improvement in the 2017 *FINDS*.

Paid employment



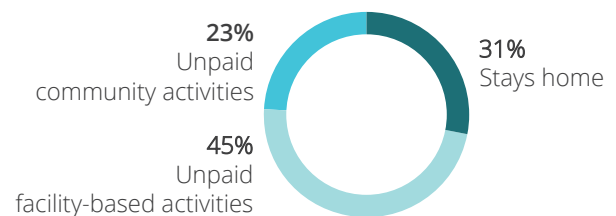
Person supported wants a paid job

Two-thirds of the people supported ages 22 and older do not have paid employment (64%). Of those, *FINDS* respondents report that nearly half (45%) would like to be employed. The 2015-2016 *National Core Indicators Adult Consumer* survey reports that 81% of individuals with IDD do not have a paid community job with 47% of those indicating that they would like paid employment (HSRI & NADDDDS 2017d). The number employed in the *FINDS* survey includes those who are doing paid work in center-based programs. This accounts for 23% of those reported to have paid employment.

Day supports and activities

One in four of the individuals supported, who did not have paid employment, stays home during the day (31%). Most are in unpaid facility-based programs such as day programs (45%) or participating in unpaid community activities such as volunteering (23%). About 4% of the individuals supported were reported to be in school. Individuals with household incomes below the median were more likely to be home during the day (29%) than those with higher household incomes (20%). Unpaid center-based programs were more common among households below the median (37%) versus those above the household median income (34%). Non-white caregivers also reported that their family member was more likely to be home during the day (27%) than did white caregivers (23%).

Day supports and activities

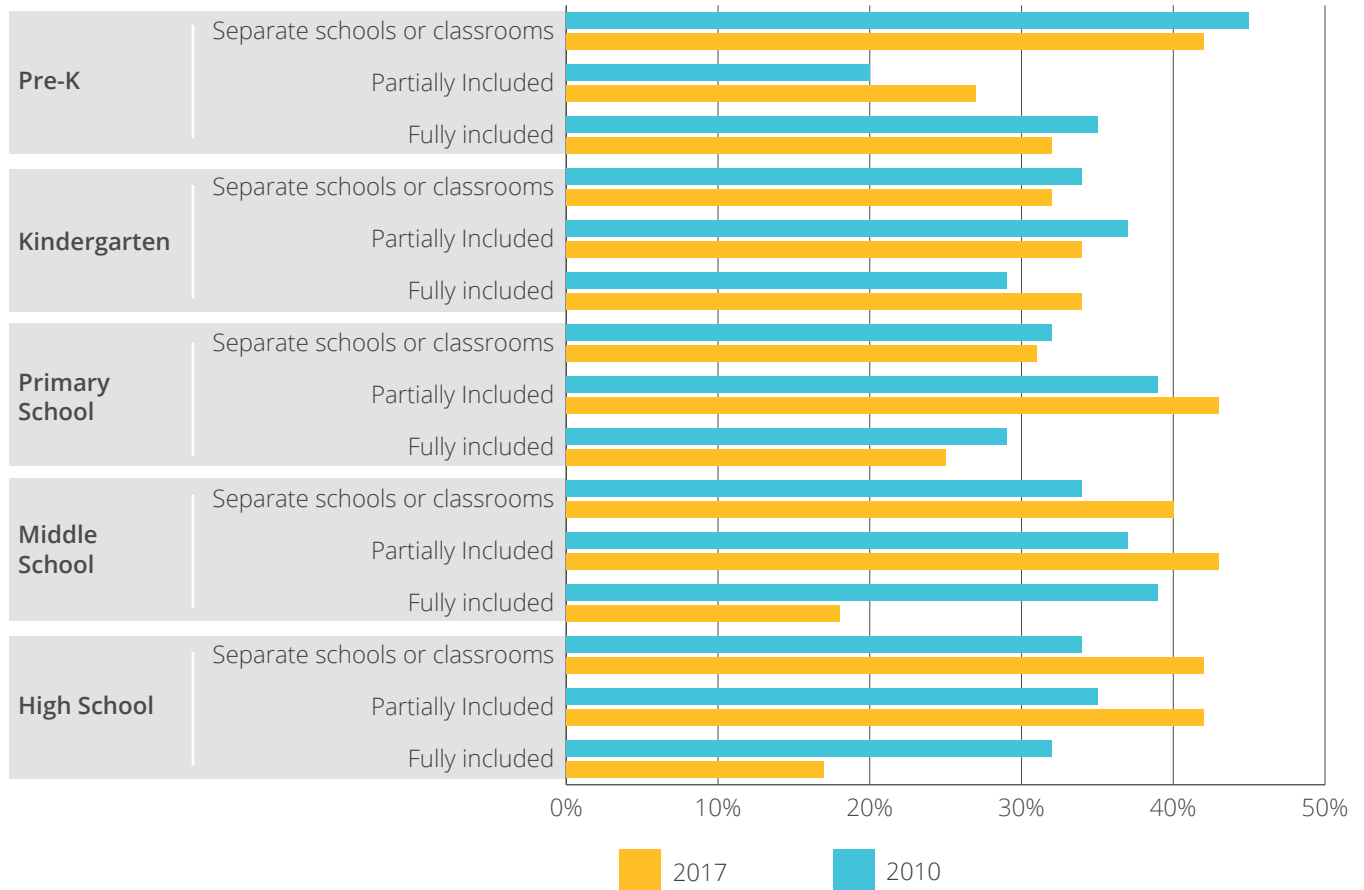


Community Inclusion

School inclusion

Full inclusion in school is highest during kindergarten (34%), followed by preschool (32%). The older students were, the less frequently *FINDS* Caregivers reported that their family member was fully included in school classrooms (primary school, 25%; middle school 18%; high school, 17%). Separate schools or classrooms were most common in pre-kindergarten (42%), middle school (40%), and high school (42%). Fewer students were reported to be in separated classrooms than in the 2010 *FINDS*, however, reports of full inclusion into classrooms has decreased across all grades other than kindergarten since 2010. The number of students reported to be in partially included classrooms has increased across all school levels since the 2010 *FINDS* survey with the exception of kindergarten which decreased from 37% to 34% (pre-kindergarten, 20% to 27%; primary school, 39% to 43%; middle school 37% to 43%, high school, 35% to 43%). Kindergarten increased in the numbers of students fully included in their classrooms from 29% to 34%.

School inclusion



Across all grade levels students of color were more likely to be in disability only schools or settings than were white students.

School inclusion varied by the identified disability of the person supported. Individuals with ID and ID and ASD were much more likely to be in segregated classroom and the least likely to be in fully included classroom settings across grade levels. Individuals with other developmental disabilities were the most likely to be included across all age levels. School inclusion also differed by race. Across all grade levels students of color were more likely to be in disability only school or settings than were white students. Nearly a quarter of *FINDS* Caregivers (24%) other than white reported their child had been in a kindergarten program only for students with disabilities compared to 14% of white respondents. This held true for primary school (22% versus 15%), middle school (28% versus 20%) and high school (30% versus 23%).

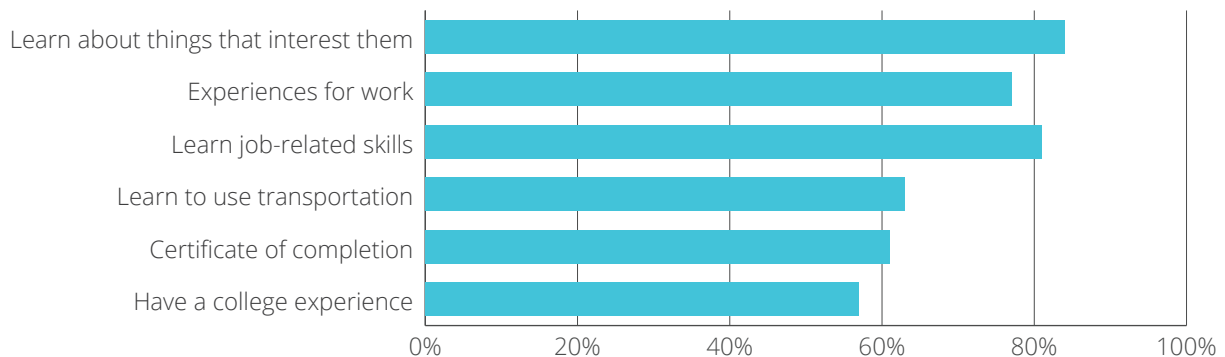
Post-secondary education

Three of four *FINDS* Caregivers (76%) thought that post-secondary education was somewhat or very important for the individual they supported. This is a decrease from the 2010 *FINDS* in which 84% of the Caregivers thought post-secondary education was either somewhat or very important. It is also lower than the expectation that nine out of ten parents generally expect that their children will acquire at least some post-secondary education (Lipman, et al, 2008).

More than half of the *FINDS* Caregivers responding to this question identified these reasons why post-secondary education might be important to the individual they support, including to:

- to learn about things they are interested in (84%),
- to learn job-related skills (81%),
- to gain experiences for work (77%),
- to learn how to use transportation options (63%),
- to obtain a non-credit skill or certificate of completion (61%), and
- to have a college experience like their non-disabled peers (57%).

Post-secondary education



Social activities

FINDS Caregivers overwhelmingly reported that one of the supports they provide for the individual they support is assistance with arranging social and leisure activities (91%). One in five (18%) did not find this difficult. Nearly a third of *FINDS* Caregivers (32%) found supporting social and leisure activities to be difficult or very difficult. Caregivers of individuals with ID and ASD (39%) or ASD (37%) were more likely to report that this was a difficult or very difficult task.

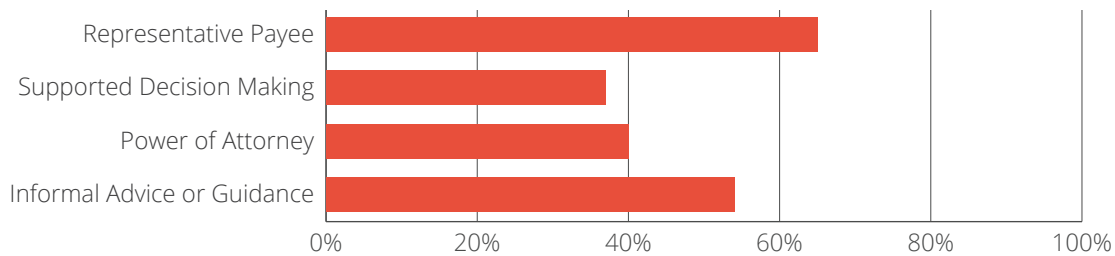
Rights, choice and supports

Guardianship status and alternative decision-making

More than half of the individuals supported ages 18 and older had a court-appointed legal guardian (58%). In most instances, the *FINDS* respondent serves as the guardian (92%). Individuals with ID (59%) and ID and ASD (73%) were more likely to have a court appointed guardian than were people with ASD (48%) or people with other disabilities (43%). Guardianship differed by race with white Caregivers reporting higher guardianship rates for their adult family member (58% versus 51%).

Before obtaining guardianship, 66% of the caregivers considered having a representative payee, 37% considered supported decision-making, 41% considered power of attorney, and 54% considered providing informal advice and guidance to the person they support.

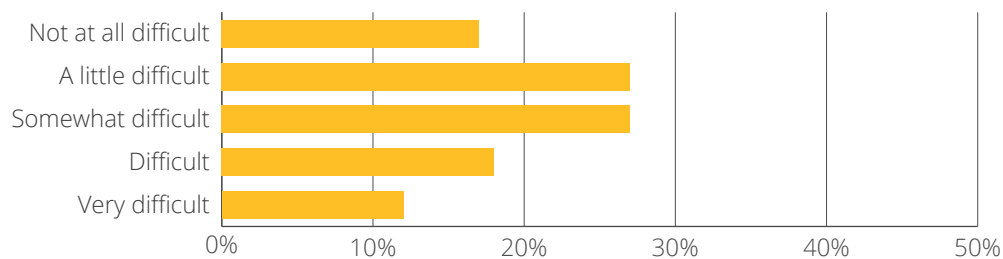
Alternative decision-making considered before guardianship



Self-directed services

Roughly one third of the individuals supported use self-directed services (33%). Individuals with ASD (26%) were the least likely to use self-directed supports, while individuals with ID and ASD were the most likely (38%). Eight of ten caregivers reported some level of difficulty with self-directed services. About half (54%) reported that using self-directed services was a little or somewhat difficult, while 29% reported that it was difficult or very difficult.

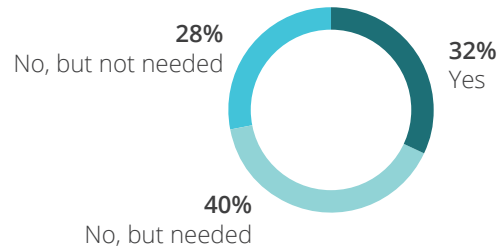
Self-directed services



Advocacy services and training

About 32% of caregivers reported that the person they support receives advocacy and training, and 19% think more is needed. Of the caregivers that reported no advocacy and training services (68%), 40% indicated that it was needed. Caregivers of individuals with ASD were the least likely to report receiving advocacy services and training (28%), but were the most likely to report that it was needed if not being received (51%). These findings are similar to the *NCI Adult Consumer Survey* in which 28% of individuals with IDD had participated in a self-advocacy event (or had the opportunity to do so and declined) (HSRI & NASDDDS, 2017d).

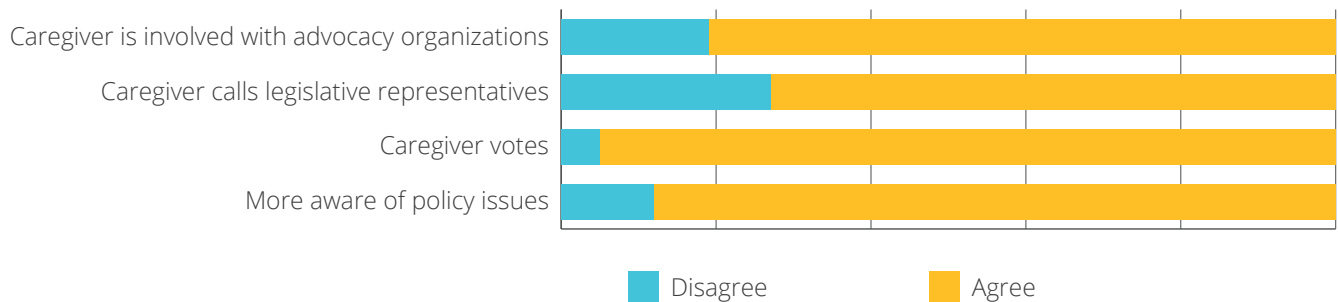
Advocacy services and training



Caregivers are advocates

FINDS caregivers reported high involvement with various advocacy activities. Nearly nine in ten (88%) report being more aware of policy issues; 78% report voting; 73% report calling their elected officials; and, 82% are involved with advocacy organizations. By comparison, the Census Bureau reports that only about 61% percent of the general population voted in the 2016 election (2017).

Caregiver advocacy

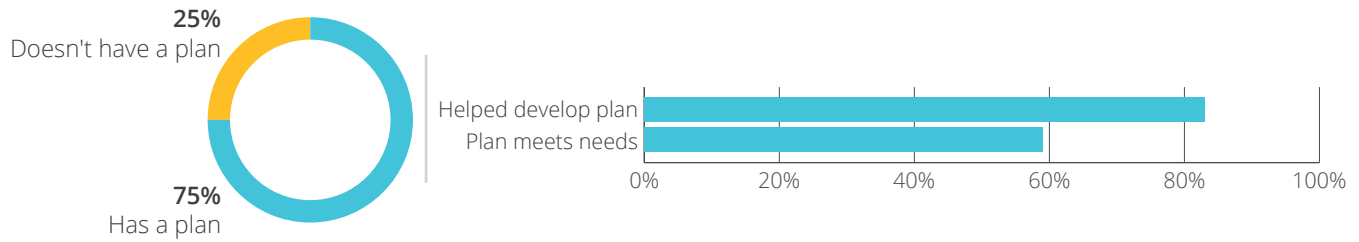


Person-Centered Supports

Supports plans

Most *FINDS* Caregivers (75%) reported that the person they supported had an individual support plan. Of those reporting they had a plan, 83% indicated that they and the person they supported helped develop the plan. However, only 59% thought that the plan addressed all of the needs of the person they supported. Individuals with ID (82%) or ID and ASD (81%) were more likely to have a support plan than were people with ASD (65%) or people with other developmental disabilities (67%). Half of the caregivers who supported individuals with ASD reported that the plan met support needs, as did 60% of caregivers for individuals with ID and ASD, 61% of those with ID, and 63% of those with other developmental disabilities.

Supports plans

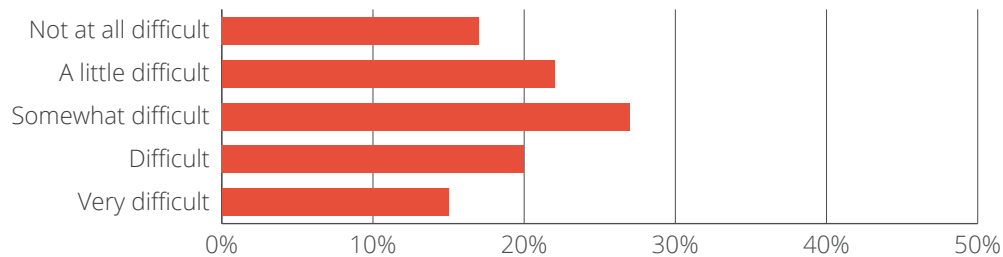


About the same proportion of *FINDS* Caregivers (76%) indicated that they supported their family member with person-centered planning. Most (52%) found this to be a little or somewhat difficult, while 16% did not think it was difficult at all and 31% found it difficult or very difficult. Caregivers of individuals with ID (82%) or ID and ASD (83%) were more likely to support the development of a person-centered plan caregivers of individuals with ASD (69%) or other disabilities (71%).

Caregiver supports self-advocacy

Most *FINDS* Caregivers (92%) reported that they supported self-advocacy activities for their family member. Some (17%) did not find this at all difficult. However, 49% found supporting self-advocacy to be a little or somewhat difficult, while 35% found it to be difficult or very difficult. *FINDS* Caregivers who provided supports to individuals with other developmental disabilities were the most likely to report no difficulty supporting self-advocacy (24%), while caregivers of individuals with ID and ASD (41%) and ASD (38%) were more likely to report that this was difficult or very difficult.

Caregiver supports self-advocacy



Top 3 services important for well-being

FINDS Caregivers were asked to list the three most important things for the well-being of the individuals they support.

- support for activities of daily living
- health care and in-home medical supports (such as medication management)
- finding, coordinating, and monitoring support services

Future Planning

Plan for the future

Most caregivers (54%) reported that they did not have a plan for the future of the person they support. Caregivers of individuals with ID (51%) were the most likely to indicate that they had a plan, followed by caregivers of individuals with ID and ASD (45%), other developmental disabilities (44%) and ASD (35%). Caregivers with lower household incomes were less likely to report having a plan for the future (40%) than caregivers with higher household incomes (48%).

Most caregivers (54%) reported that they did not have a plan for the future.

Ideal living arrangements

Caregivers were asked to identify what they thought was the ideal living arrangement for their family member with IDD. Most caregivers (48%) wanted their family member to live where they currently lived (80% of caregivers lived with their family member). 15% would like their family member to live in their own home and 16% in an intentional community that included people with and without disabilities. Relatively few caregivers identified congregate care of any size (5%) or living in someone else's home (3%) as ideal living arrangements.

Worries about the future

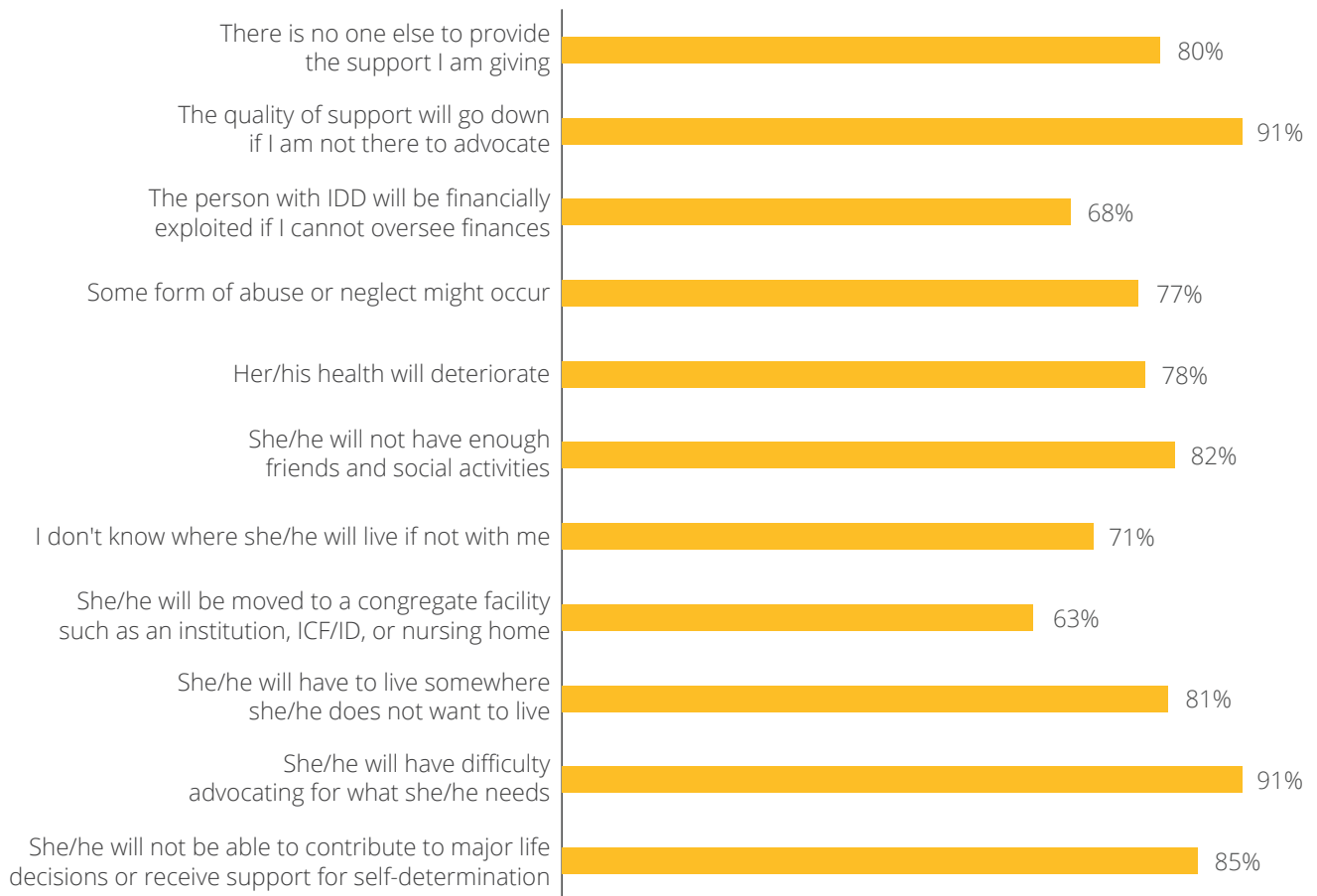
FINDS Caregivers had a number of worries about the future of the individual they supported should they no longer be available to provide support. More than half identified the following concerns:

- quality of support will decrease if I am not there to advocate (91%);
- s/he will have difficulty advocating for what s/he wants (91%);
- s/he will not be able to contribute to major decisions or receive support for self-advocacy (85%); s/he will not have enough friends and social activities (82%);
- s/he will have to live somewhere they don't want to (81%);
- there is no one else to provide they support I am giving (80%);
- his/her health will deteriorate (78%);
- some form of abuse or neglect will occur (77%);
- I don't know where s/he will live (71%);
- the person will be financially exploited (68%); and
- s/he will have to move to a congregate care facility such as an institution or a nursing facility (63%).

Caregivers identifying as white were somewhat less likely to be worried about financial exploitation (67%), abuse or neglect (77%), or that their family member will have to move to a congregate care facility (62%) than were caregivers from other backgrounds (76%; 82%; 68%).

Nine in ten (92%) indicated difficulty with finding DSPs

Worries about the future



Direct Support Workforce

Difficulty finding direct support professionals

Two-thirds of FINDS Caregivers (68%) reported that they assisted the individual they support with finding direct support professionals (DSPs). FINDS Caregivers supporting individuals with ID and ASD (75%) and ID (70%) were much more likely to report providing this support. Nine in ten (92%) indicated difficulty with finding DSPs. More than half (54%) said that it was difficult or very difficult to find DSPs. Caregivers supporting individuals with ID and ASD (60%) were the most likely to report difficult or great difficulty finding DSPs, followed by those supporting individuals with ASD (56%), ID (52%) and other developmental disabilities (46%).

More than half of caregivers (61%) reported that they assisted with finding respite care and 92% experienced some level of difficulty with this.

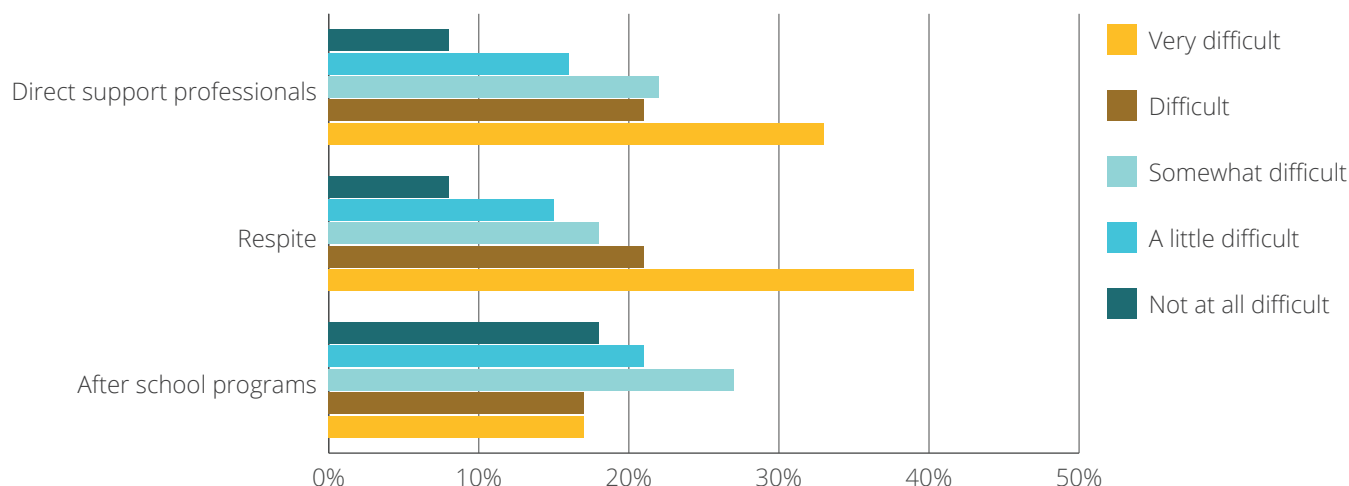
Difficulty finding respite care

More than half of *FINDS* Caregivers (61%) reported that they assisted with finding respite care and 92% experienced some level of difficulty with this. Caregivers of individuals with ID and ASD were the most likely to use respite (69%) and ID (62%). Caregivers of individuals with ASD (57%) and other developmental disabilities (53%) were somewhat less likely to use respite. More than half of the caregivers of individuals with ID (52%), ASD (56%) or ID and ASD (60%) reported that it was difficult or very difficult to find respite care.

Difficulty finding afterschool/childcare

Four of ten *FINDS* Caregivers (40%) reported that they supported the individual with disabilities with obtaining childcare or afterschool care. Caregivers of individuals with ID (30%) were the least likely to report this support, while caregivers of individuals with ASD (49%) were the most likely to report this. More than half of *FINDS* Caregivers (58%) reported a little or some difficulty with finding childcare, while 34% found it difficult or very difficult. Caregivers of individuals with other developmental disabilities (31%) were more likely to report having no difficulties finding childcare. However, 41% of caregivers of individuals with ID and ASD reported that finding childcare was difficult or very difficult.

Difficulty finding afterschool/childcare



Summary

Review of key findings

While there are a few bright spots, such as more individuals with IDD in competitive employment and making minimum wage, and fewer students in separate classrooms since the 2010 *FINDS* report, caregivers of individuals with IDD needing support identify numerous unmet needs for the individual they support as well as for themselves. The *FINDS* Caregivers reflect the ever-increasing reliance on families to provide the bulk of supports to individuals with IDD. Supports that can have a positive impact on both the caregiver and the individual being supported, such as respite to allow for some time apart, are in short supply. For families that do have in-home support services, the difficulty finding direct support professionals can cause challenges for the caregivers as well as for the individual supported. Caregivers report a number of economic impacts such as needing to quit work, reduce hours, or turn down promotions

in order to provide care. Paired with the reliance on families to provide long-term supports is the aging population of caregivers; this adds stress and challenge for families.

Despite the general lack of diversity in the *FINDS* participant sample, there were still some important differences related to both race and economic status. *FINDS* Caregivers other than white were younger and cared for younger individuals who were more likely to report as having ASD. For example, these individuals were more likely to be in segregated settings during their school careers and less likely to be working in any sort of paid employment when they were adults and more likely to be at home during the day. Being able to understand the differences across the breadth of cultural and linguistic diversity of the U.S. isn't possible due to the limited sample sizes.

FINDS shows the economic strain that caregivers experience. Caregivers with household incomes of less than \$59,000 per year reported higher negative effects stemming from their caregiving opportunities than did those with higher household incomes. We were not able to determine the extent to which caregiving had a direct impact on household income related to missed job opportunities.

FINDS also shows that the community support system needs strengthening to enable it to better serve the needs of individuals with ASD. Given the growing prevalence of ASD, understanding how best to support and meet the needs of these individuals is an important step for the service system.

FINDS Caregivers report a number of challenges that may explain the levels of stress and fatigue reported by caregivers. The scope, intensity and duration of caregiving responsibilities for *FINDS* Caregivers is greater than that reported by other caregivers (e.g., *Caregiving in the U.S.* survey Caregivers). These responsibilities coupled with challenges finding adequate supports for their family member explain the high levels of stress reported by *FINDS* Caregivers and highlight the need for more attention on caregiver supports.

Policy and other implications

The reported challenge of the direct support workforce has significant policy implications. As services and supports have become increasingly individualized paired with an aging population, the need for an increasing number of workers trained to provide community supports to people with a variety of needs is apparent. In addition, the number of individuals waiting for services while living in the family home is an additional concern as the caregiving population ages. The economic impacts of caregiving have implications as aging caregivers reach retirement and have increased care needs of their own.

Although efforts such as Employment First, Consumer Directed Supports and similar policies have been developed to promote the full inclusion of people with disabilities into their communities, it is clear that these efforts are not working for all individuals with IDD. Caregivers often know the supports the person they supports needs and wants, but accessing those supports can be a challenge due to limited access, workforce or availability.

References

- Anderson, L.L., Larson, S.A., Kardell, Y., Taylor, B., Hallas-Muchow, L., Eschenbacher, H.J., Hewitt, A.S., Sowers, M., & Bourne, M.L. (2016). Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Butterworth, J., Hiersteiner, D., Engler, J., Bershadsky, J., & Bradley, V. (2015). National Core Indicators©: Data on the current state of employment of adults with IDD and suggestions for policy development. *Journal of Vocational Rehabilitation*, 42(3), 209-220.
- Heller, T., Hsieh, K., & Rowitz, L. (1997). Maternal and paternal caregiving of persons with mental retardation across the lifespan. *Family relations*, 407-415.
- HSRI & NADDDDS. (2017a). Child Family Survey 2015-2016 Final Report. Retrieved from https://www.nationalcoreindicators.org/upload/core-indicators/CFS_2015-w_all_edits_3_9.pdf
- HSRI & NADDDDS. (2017b). Adult Family Survey 2015-2016 Final Report. Retrieved from https://www.nationalcoreindicators.org/upload/core-indicators/FINAL_AFS_updated_2_15.pdf
- HSRI & NADDDDS. (2016). Family/Guardian Survey 2015-2016 Final Report. Retrieved from https://www.nationalcoreindicators.org/upload/core-indicators/FGS_2015-16_w_all_edits_1_251.pdf
- HSRI & NADDDDS. (2017c). Adult Consumer Survey 2015-2016 Final Report Part I. Retrieved from https://www.nationalcoreindicators.org/upload/core-indicators/2015-16_ACS_Report_Part_I_0623.pdf
- HSRI & NADDDDS. (2017d). Adult Consumer Survey 2015-2016 Final Report Part II. Retrieved from https://www.nationalcoreindicators.org/upload/core-indicators/2015-16_ACS_Report_Part_II_NCI_History_and_Activities_and_Appendices.pdf
- Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (in press, 2018). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Lippman, L., Guzman, L., Dombrowski Keith, J., Kinukawa, A. Schwalb, R., and Tice, P. (2008). Parent Expectations and Planning for College: Statistical Analysis Report (NCES 2008-079). National Center for Education Statistics, Institute of Education Sciences, U.S. Department of Education. Washington, DC.
- National Alliance for Caregiving. (2015). Caregiving in the U.S. Washington, DC: National Alliance for Caregiving. Retrieved from http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf.
- Pew Research Center (2017). Facttank, News in Numbers: Record shares of Americans now own smartphones, have broadband at home. Retrieved from <http://www.pewresearch.org/fact-tank/2017/01/12/evolution-of-technology/>. January 12, 2017.
- U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2013). The National Survey of Children with Special Health Care Needs: Chartbook 2009-2010. Rockville, Maryland: U.S. Department of Health and Human Services. Retrieved from <https://mchb.hrsa.gov/cshcn0910/more/pdf/nscshcn0910.pdf>
- U.S. Census Bureau (2017). Voting in America: A Look at the 2016 Presidential Election. Retrieved from https://www.census.gov/newsroom/blogs/random-samplings/2017/05/voting_in_america.html February, 2018.
- Yavorsky, J. E., Kamp Dush, C. M., & Schoppe-Sullivan, S. J. (2015). The production of inequality: The gender division of labor across the transition to parenthood. *Journal of Marriage and Family*, 77(3), 662-679.