Disability Data Digest 2018

A collection of infographics presented by:

medisked
A connected agency means better care.

The Arc.
For people with intellectual and developmental disabilities
Friends,

It is with great pleasure that MediSked and The Arc of the United States present the 2018 Disability Data Digest — a scoping compilation of the latest statistics on intellectual and developmental disabilities (I/DD) services and supports displayed in an easy to read infographic format. This report provides a snapshot of today’s disability community and highlights the areas in which progress has been made toward achieving parity in access to opportunity and basic human rights, while also delineating the many challenges that still face individuals with I/DD in striving for inclusion and equality.

In addition to providing an overview of data related to the disability community, this report is also a tool with which disability rights advocates, policy makers, practitioners, and self-advocates can create data-driven arguments that can further the local and national disability rights agendas. This is why we have included a fact sheet at the end of this report that is linked to resources and databases which contain state-specific data to support local-level advocacy campaigns. We encourage you to use these resources in your advocacy efforts.

MediSked continues to push the boundaries of technology to improve the quality of life, personal outcomes, and choices for the people with I/DD receiving supports throughout the continuum of care — from state level offices through provider agencies. The Arc is and has always been a beacon for advocacy for people with I/DD and their families. The organization continues to lead the way for a person-centered approach to supports and services.

Thank you!

Doug Golub
President, MediSked, LLC

Peter Berns
Chief Executive Officer, The Arc
Population and Demographics

National disability prevalence statistics vary greatly as the definitions of disability in data gathering instruments and data gathering methodologies have not always fully included people across the disability spectrum. As a result, the most accurate statement regarding national disability prevalence is that there are between 39.9 million and 57 million people with disabilities living in the United States.

Disability prevalence data by race/ethnicity
(based off of 2016 ACS 5 year estimates)

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
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</thead>
<tbody>
<tr>
<td>Black or African American alone</td>
</tr>
<tr>
<td>White alone</td>
</tr>
<tr>
<td>American Indian and Alaska Native alone</td>
</tr>
<tr>
<td>Asian alone</td>
</tr>
<tr>
<td>Native Hawaiian &amp; Other Pacific Islander alone</td>
</tr>
<tr>
<td>Some other race alone</td>
</tr>
<tr>
<td>Two or more races</td>
</tr>
</tbody>
</table>

Source: U.S. Census Bureau, 2012-2016 American Community Survey 5-Year Estimates
Disability prevalence data by type of disability

- Deaf or hard of hearing: 11,089,041
- Blind or visually-impaired: 7,231,542
- Cognitive disabilities, i.e. difficulty remembering, concentrating, etc.: 14,806,529
- Mobility Impaired: 20,649,180
- Self-care difficulty, i.e. difficulty bathing, dressing, etc.: 7,877,505
- Independent living difficulty, i.e. difficulty doing errands alone such as visiting a doctor’s office or shopping: 13,940,629

Source: U.S. Census Bureau, 2012-2016 American Community Survey 5-Year Estimates
Persons with cognitive disabilities responded “YES” to “having difficulty remembering, concentrating, or making decisions (DREM).”

Persons with self-care difficulty responded “YES” to “having difficulty bathing or dressing (DDRS).”

Persons with independent living difficulty responded “YES” to “having difficulty doing errands alone such as visiting a doctor’s office or shopping (DOUT).”

Source: U.S. Census Bureau, 2012-2016 American Community Survey 5-Year Estimates
An estimated 7.37 MILLION people in the US had some form of intellectual or developmental disability in 2016

Source: Larson et al., 2018

New autism prevalence statistics

A study conducted by the Centers for Disease Control and Prevention reported that the estimated prevalence rate for autism among individuals in the U.S. is 1 IN 59 CHILDREN (1 IN 38 BOYS, 1 IN 152 GIRLS)

Source: The Centers for Disease Control, 2018
Socio-Economic Profile

Despite its relatively large representation among the U.S.’ total population, the disability community remains one of the most socioeconomically depressed subgroups in the country. Issues such as unemployment, homelessness, and food insecurity are still felt by many individuals with disabilities.

Poverty rate and average income per household

30%  
Poverty rate among adults with disabilities aged 18-59  
2x more than people without disabilities in same age group  
Source: National Health Interview Survey, 2015

Median earnings

$31,865+  
People with a disability  
$21,509  
People with no disability  
Source: U.S. Census Bureau, 2012-2016 American Community Survey 5-Year Estimates.

40%  
of people with disabilities experience a material hardship such as low-quality housing, difficulty paying bills, unmet need for health care, or inadequate food.  
Source: Center on Budget and Policy Priorities / Carlson et al., 2017
Supplemental Security Income

4.8 MILLION
adults with disabilities relied on the Supplemental Security Income (SSI) program as their only source of income in 2016.
Source: Priced Out, 2017

Supplemental Security Income is only $763 PER MONTH (national average)

The average annual income of a single person receiving Supplemental Security Income payments in 2016 was $9,156 — about 22% below the federal poverty level, and equal to only 20% of the national median income for a one-person household.
Source: Schaak et al., 2017

Spending power and financial capability

<table>
<thead>
<tr>
<th>The National Disability Institute’s National Financial Capability Study</th>
<th>People with a disability</th>
<th>VS</th>
<th>No Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inability to come up with $2,000 if an unexpected need arose in the next month</td>
<td>37%</td>
<td>18%</td>
<td></td>
</tr>
<tr>
<td>Likely to have checking account</td>
<td>84%</td>
<td>91%</td>
<td></td>
</tr>
<tr>
<td>Likely to have savings account</td>
<td>61%</td>
<td>77%</td>
<td></td>
</tr>
<tr>
<td>More likely to be unbanked</td>
<td>12%</td>
<td>6%</td>
<td></td>
</tr>
</tbody>
</table>

Source: National Disability Institute, 2017

40% of people with disabilities experience low-quality housing, difficulty paying bills, unmet need for health care, or inadequate food
Source: Rivera Drew, 2015
SNAP benefits are extremely modest, averaging $187 per month for non-elderly adults with disabilities in 2016 — or just $6 per day.

Source: U.S. Department of Agriculture, 2017
Employment

Access to meaningful employment for people with disabilities continues to be an issue across the country. Many individuals with disabilities of working age are either unemployed or do not participate in the workforce due to lack of opportunity, poor education attainment levels, and many other factors. Despite a growing trend of states moving away from funding sheltered work programs in favor of funding community-based, integrated employment programs, many individuals with disabilities remain in underpaid and sheltered work environments.

Labor force participation rate

22% People with disabilities (including physical, intellectual and developmental, sensory, and other disability categories) aged 16 and over

68% People without disabilities of the same age
Labor force participation of persons with disabilities in the U.S., 2016

Total people with cognitive disabilities of working age in 2016:
8,931,533
67% not in labor force in 2016
26% in labor force in 2016

Total people with independent living difficulties of working age in 2016:
7,412,570
79% not in labor force in 2016
17% in labor force in 2016

Total people with self care difficulties of working age in 2016:
3,653,028
82% not in labor force in 2016
15% in labor force in 2016

Source: American Community Survey 2016 1-year estimates
Employment statistics by setting

In 2015, only **18.6%** of individuals of working age served by state I/DD agencies were employed in integrated settings.

- **22%** were supported in facility-based work settings
- **53%** were supported in facility-based non-work settings
- **43%** were supported in community-based non-work setting


Employment wage statistics

U.S. National Average Hourly Wage:

- **$24.34**

U.S. National Average Hourly Wage for people with disabilities of working age:

- **$14.56**

Health

People with disabilities often experience poor health outcomes due to lack of access to healthcare, poor diet resulting from food insecurity issues, and basic education in making healthy lifestyle choices. Recently, the Centers for Disease Control and Prevention, The Arc, and other national entities have endeavored to promote healthier lives for people with disabilities. Despite these efforts, some disparities between the disability community and people without disabilities remain.

Lurie Institute at Brandeis University conducted a survey which measured health outcomes for respondents with autism and other intellectual and developmental diagnoses from 35 states and Washington, D.C..

23% of adults with autism and I/DD reported fair or poor health. 10% reported fair or poor health in a similar study in 2015.

- 29% reported at least one chronic health condition such as hypertension, high cholesterol, or diabetes.
- 20% did not exercise or do physical activity regularly.
- 60% were overweight or obese.

Source: Li, H., 2017
Obesity

29% of respondents of the Adult Consumer Survey of 2016-2017 reported being overweight
35% reported being obese


Just as obesity is a growing public health problem in the general population, it is emerging as a critical disparity issue for people with I/DD.

RATES OF OBESITY

People with intellectual disabilities:

WOMEN: 43%
MEN: 34%

People without intellectual disabilities:

27% 28%

Source: K. Hsieh et al. 2014

Physical activity

Of the respondents surveyed in 2016-2017 by NASDDDS and HRSI:

77% of respondents said that they went out to exercise regularly

Sometimes: 1-2x a week
Regularly: 3x a week

Independence and Decision-Making

Whether people are living with family members, in group homes, or on their own, an individual’s ability to choose how they want to spend their free time, who their friends are, what kind of job they want to have, and where they want to live is essential in living an independent and fulfilling life.

Of the individuals surveyed for the 2016-2017 Adult Consumer Report by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and Human Services Research Institute (HRSI):

- 83% decide what their daily schedule will consist of on a regular basis.
- 87% decide how to use their spending money.
- 30% chose who their roommates would be or chose to live alone.
- 86% chose or had some help choosing where they work.
- 25% participate in self-advocacy meetings.

Living in the Community

Since the deinstitutionalization movement began over 40 years ago, the number of people with disabilities living in institutional settings (and the number of institutions) has continued to decline. There are still a number of institutions that remain in operation across the country, despite evidence of community-based residential settings providing better quality of life for individuals with disabilities and cost-savings for states.

Living at home

71% of all individuals with I/DD received residential care and supports from family members and caregivers.

Living in out-of-home settings

The annual publication State of the States in Intellectual and Developmental Disabilities reports that in 2015:

- 680,851 individuals with I/DD lived in out-of-home settings
- 50% lived in supported living and/or personal assistance settings
- 70,000 persons with I/DD lived in settings with 16 or more persons which include nursing facilities, state institutions, and intermediate care facilities

Source: Braddock et al., 2017
Housing

Finding affordable housing is a challenge that many Americans face, especially in urban settings. This task is especially daunting for people with disabilities, many of whom rely on government assistance programs as their sole income if they're unemployed and who earn significantly less (on average) that people without disabilities if they are employed.

$763
National average for Supplemental Security Income (SSI)

$861
National average monthly rent for a basic one-bedroom apartment

RENT BURDENED:
Those that pay more than 40% of their income

WORST CASE NEEDS:
Households that pay more than 50% of their income for housing costs and/or live in seriously substandard housing

Worst case needs households that included a non-elderly person with disabilities

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Homeless Individuals</th>
<th>Change</th>
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<tbody>
<tr>
<td>2013</td>
<td>1.08 million</td>
<td></td>
</tr>
<tr>
<td>2017</td>
<td>1.39 million</td>
<td>28%</td>
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(Source: Schaak et al., 2017, Worst Case Housing Needs Report to Congress 2017)

369,081 total homeless individuals
living emergency shelters, transitional housing, on the streets or in places not meant for human habitation identified in the 2017 AHAR

86,962 were chronically homeless
A person is considered chronically homeless if they have a disability and if they have been continuously homeless for one year or more or have experienced at least four episodes of homelessness adding up to at least 12 months in the last three years.

(Source: Henry et al., 2017)
Long Term Supports and Services (LTSS)

The demand for long term supports and services is growing and, despite yearly increases in expenditures in LTSS, state DD agencies are falling behind relative to the need for support services. As a result, the vast majority of individuals with disabilities are unable to receive the supports they need to live independent and fulfilling lives.

5.5 MILLION

individuals with I/DD do not receive any kind of direct support services from state I/DD agencies in 2016

20% were known to or served by state I/DD agencies
17% received long-term supports or services

Source: Larson et al., 2017

$44,112
Medicaid waiver average cost per person by year (2015)

$134,630
Medicaid intermediate care facilities average cost per person by year

423,735
National waiting list enrollment for HCBS Medicaid waiver services (1915(c) and 1115 waivers) for people with I/DD in (2016)

States with the highest number of people waiting for services:

196,248  
TEXAS

64,546  
OHIO

20,751  
FLORIDA

Source: Larson et al., 2017
Source: Kaiser Family Foundation, 2016
Direct Support Professional Crisis: By The Numbers

Direct Support Professionals (DSPs) provide vital services that allow for individuals with I/DD to live in the community, live independently, socialize, and enter the workforce. Family members and other natural supports rely on DSPs to provide quality support and care to individuals so that these at-home caregivers can also work and have respite from providing care. Despite their vital role and increasing demand for DSP services, the national LTSS industry is in a crisis, as many DSPs are working longer hours for very little income.

Here are some of the numbers reported in the Report to the President 2017: America’s Direct Support Workforce Crisis by the President’s Committee for People with Intellectual Disabilities:

Average DSP wages
$10.72 PER HOUR

Average DSP wages
BELOW THE FEDERAL POVERTY LEVEL
FOR A FAMILY OF FOUR

ONLY 10% of DSPs are offered employee benefits

Most DSPs work two or three jobs

Half of DSPs rely on government-funded and means-tested benefits

Average annual DSP turnover rates 45%

Source: President’s Committee for People with Intellectual Disabilities, 2017
Family Caregiving & Natural Supports

Family caregivers and natural supports provide the most direct — and often the only — source of personal care and support for individuals with I/DD. Providing constant care for individuals with I/DD who live at home is a challenge to most family caregivers, particularly those who are working and those who are aging. As the demand for in-home care and life expectancy for individuals with I/DD continue to rise, family caregiver and other natural supports are under pressure to provide more care for longer than ever before.

The State of the States Report 2017 estimates that

- 70% of individuals with I/DD live with a family caregiver
- 16% of individuals with I/DD live alone
- 14% live in supervised residential settings

The State of the States report cited above found that in 2015 more than 871,000 people with I/DD lived with caregivers who are 60 years of age or older.

This figure will continue to grow, as more and more caregiving parents of children with disabilities continue to get older.

Source: Braddock et al., 2017
Challenges facing unpaid caregivers

The 2017 FINDS Survey of Caregivers reported that 48% WERE EITHER VERY OR EXTREMELY STRESSED by having to provide care for an individual with I/DD.

The average amount of hours of support that caregivers provide to individuals with I/DD per week:

- 57

As a result of these long hours, these are some of the main challenges facing individual caregivers:

- 85% balancing family responsibilities
- 82% are physically fatigued
- 82% dealing with breakdowns in support
- 76% meeting work responsibilities

Source: Anderson et al., 2018
The FINDS survey asked caregivers to identify some areas in which they need more supports/resources. These were some of their main points:

- **60%** Providing direct financial support
- **58%** Arranging for, managing benefits
- **58%** Finding respite services
- **57%** Finding PCAs, DSPs
- **56%** Communicating with healthcare & support professionals
Disability and the Justice System

In a time where bias and excessive use of force by police has resulted in national scrutiny of the criminal justice system, the high rates of violence against and imprisonment of people with disabilities is often overlooked. People with disabilities, especially people with “invisible” disabilities, are disproportionately represented in prison settings. Furthermore, people with disabilities, on average, are more likely to be victims of violent crimes and sexual assault than those without disabilities.

According to the Bureau of Justice Statistics

30% of people in state and federal prisons and about 40% of people in jails REPORT HAVING AT LEAST ONE DISABILITY

Source: Bureau of Justice Statistics, 2015

INDIVIDUALS WITH DISABILITIES MAKE UP A THIRD TO HALF OF ALL PEOPLE KILLED BY LAW ENFORCEMENT OFFICERS

About 2 in 10 prisoners and 3 in 10 jail inmates reported having a cognitive disability, the most common reported disability in each population.

Source: Bureau of Justice Statistics, 2015

People with I/DD face the highest victimization rates among the disability community and are 2x MORE LIKELY TO FACE VIOLENT VICTIMIZATION than their peers without disabilities.

Source: Bureau of Justice Statistics, 2017

70% of individuals on the National Registry of Exonerations reported having either a mental illness or intellectual or developmental disability diagnosis.

Source: National Registry of Exonerations at The University of Michigan

People with disabilities are 7x MORE LIKELY TO EXPERIENCE SEXUAL VICTIMIZATION

Source: National Public Radio, 2018
References


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MediSked
Founded in 2003, MediSked is the trusted partner to human services organizations across the country, delivering integrated technology solutions and expertise to improve outcomes and cost efficacy in long term service and supports delivery for state and county oversight, payers, care coordination entities and provider agencies. Working collaboratively with its clients and partners, MediSked has developed a full-featured software ecosystem, which includes the statewide data aggregation tools required to support CMS Final Rule transition plans, the capabilities needed to deliver conflict-free case management, and innovations to drive operational efficiencies and improve population outcomes. MediSked is committed to its mission to be the leading brand in holistic solutions that improve lives, drive efficiencies and generate innovations for the human services organizations that support our community.

The Arc
The Arc advocates for and serves people with intellectual and developmental disabilities (I/DD), including Down syndrome, autism, Fetal Alcohol Spectrum Disorders, cerebral palsy and other diagnoses. The Arc has a network of nearly 650 chapters across the country promoting and protecting the human rights of people with I/DD and actively supporting their full inclusion and participation in the community throughout their lifetimes and without regard to diagnosis.
The University of Minnesota’s Institute for Community Integration (ICI) published a report, “In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2016,” which contains state by state data on enrollment in long-term supports and services and per-person spending on home-based and facility-based services.

- Number of people known to the state DD agency
- Number of people served by the state DD agency (LTSS recipients)
- Number of people on the waitlist for services
- Medicaid spending per person, FY 2016
  - Medicaid waiver recipients
  - Individuals living in intermediate care facilities for people with I/DD

The Coleman Institute’s State of the States Report, 2017 provides a state by state snapshot of spending on services and supports for individuals with I/DD.

- Total public I/DD spending for services: FY 2015
- Public I/DD spending by revenue source: FY 2015
  - State
  - Federal
- Fiscal effort for I/DD services, FY 2015
  - All services and settings
  - Community/family services
  - Institutional services
- HCBS Waiver cost per participant (US: $46,500)
Employment

Use the State I/DD Agencies data source in the Institute for Community Inclusion’s StateData resource portal to learn about your state’s current employment outcomes for people with intellectual and developmental disabilities in 2015.

- Integrated employment rate of total individuals with I/DD of working age
- Integrated employment of total individuals with I/DD of working age, percentage
- Community based non-work of total individuals with I/DD of working age, percentage
- Facility-based work of total individuals with I/DD of working age, percentage
- Integrated employment funding
- Funding for facility-based work programs

Housing

Discover how affordable housing is for people who rely on Supplemental Security Income (SSI) in your hometown and state using the Technical Assistance Collaborative’s interactive data tool.

- SSI Monthly payment (US: $763)
- SSI as percentage of median income (local area)
- SSI as percentage of median income (state-wide)
- Percentage of SSI income spent on a 1 bedroom apartment (US: 113%)
  - (local area)
  - (state-wide)
- Percentage of SSI income spent on an efficiency apartment
  - (local area)
  - (state-wide)