

# Disability Data Digest 2018



A collection of infographics  
presented by:







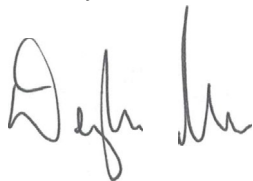
Friends,

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)

**Black or African American alone**

**White alone**

**American Indian and Alaska Native alone**

**Asian alone**

**Native Hawaiian &  
Other Pacific Islander alone**

**Some other race alone**

**Two or more races**

Source: U.S. Census Bureau, 2012-2016 American  
Community Survey 5-Year Estimates



14%

13%

17%

7%

10%

8%

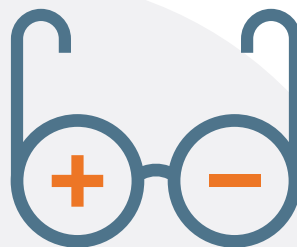
11%

## 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**

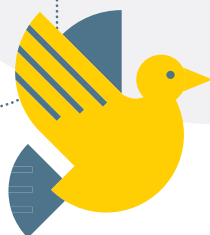


Self-care difficulty,  
i.e. difficulty bathing,  
dressing, etc.

**7,877,505**

Independent living difficulty,  
i.e. difficulty doing errands  
alone such as visiting a  
doctor's office or shopping

**13,940,629**





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)."

UTAH  
**9.4%**

lowest percentage of  
people with disabilities

WEST VIRGINIA

**19.5%**

highest percentage of  
people with disabilities

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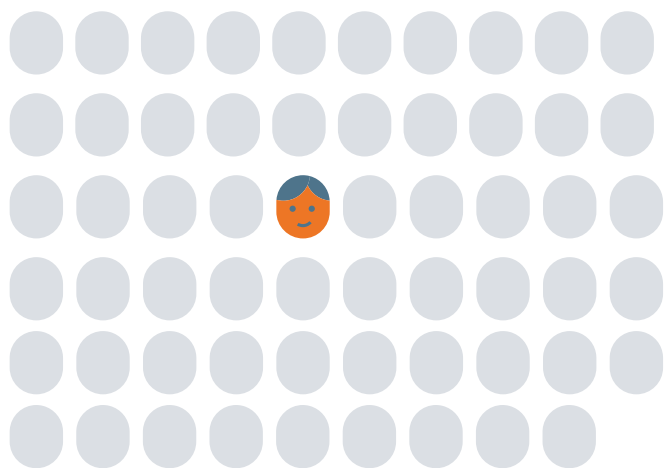
Prevalence data for people  
with I/DD

An estimated

# 7.37 MILLION

people in the US had some form of intellectual  
or developmental disability in 2016

Source: Larson et al., 2018



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## 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

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## 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

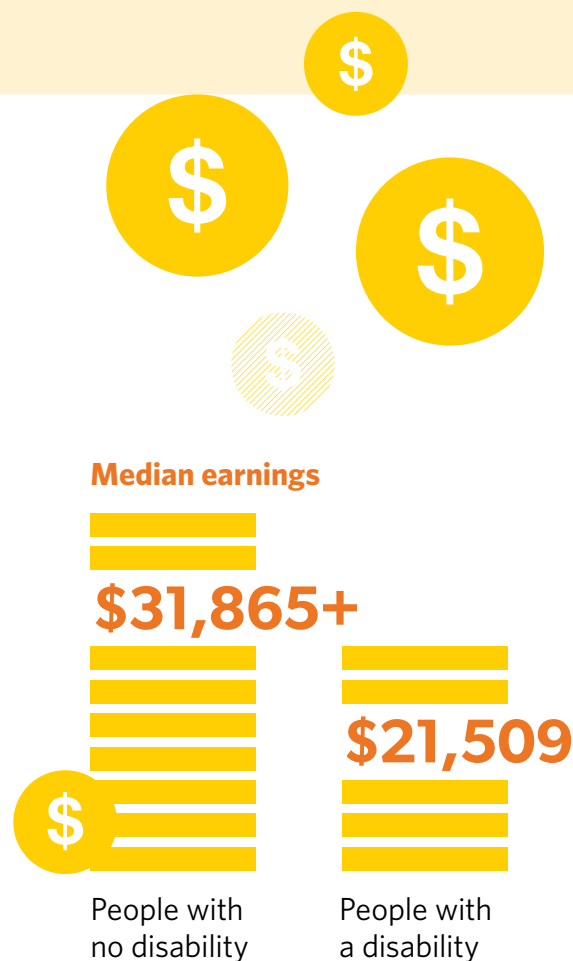
**2x more**  
than people without disabilities in same age group

Source: National Health Interview Survey, 2015

**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



Source: U.S. Census Bureau, 2012-2016 American Community Survey 5-Year Estimates.



## 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

# 40%

of people with disabilities experience low-quality housing, difficulty paying bills, unmet need for health care, or inadequate food

Source: Rivera Drew, 2015



### The National Disability Institute's National Financial Capability Study

	People with a disability	vs No Disability
Inability to come up with \$2,000 if an unexpected need arose in the next month	37%	18%
Likely to have checking account	84%	91%
Likely to have savings account	61%	77%
More likely to be unbanked	12%	6%

Source: National Disability Institute, 2017

## Food security

Families that include people with disabilities are

**2 TO 3x MORE LIKELY  
TO EXPERIENCE FOOD  
INSECURITY**

than families that have no members with disabilities



Working-age adults with disabilities are  
**4x MORE LIKELY TO LIVE WITH  
SIGNIFICANTLY LOW OR VERY  
LOW FOOD SECURITY**  
than adults without disabilities

Source: National Disability Institute, 2017

## Supplemental Nutrition Assistance Program



**4.4 MILLION**

**households that include non-elderly adults with disabilities received SNAP benefits in 2016**  
using SNAP's narrow administrative definition of "disability."

Source: U.S. Department of Agriculture, 2017

Non-elderly adults with disabilities who receive SNAP benefits have very low incomes, **averaging only about \$12,000 per year** in 2016

Source: U.S. Department of Agriculture, 2017

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.

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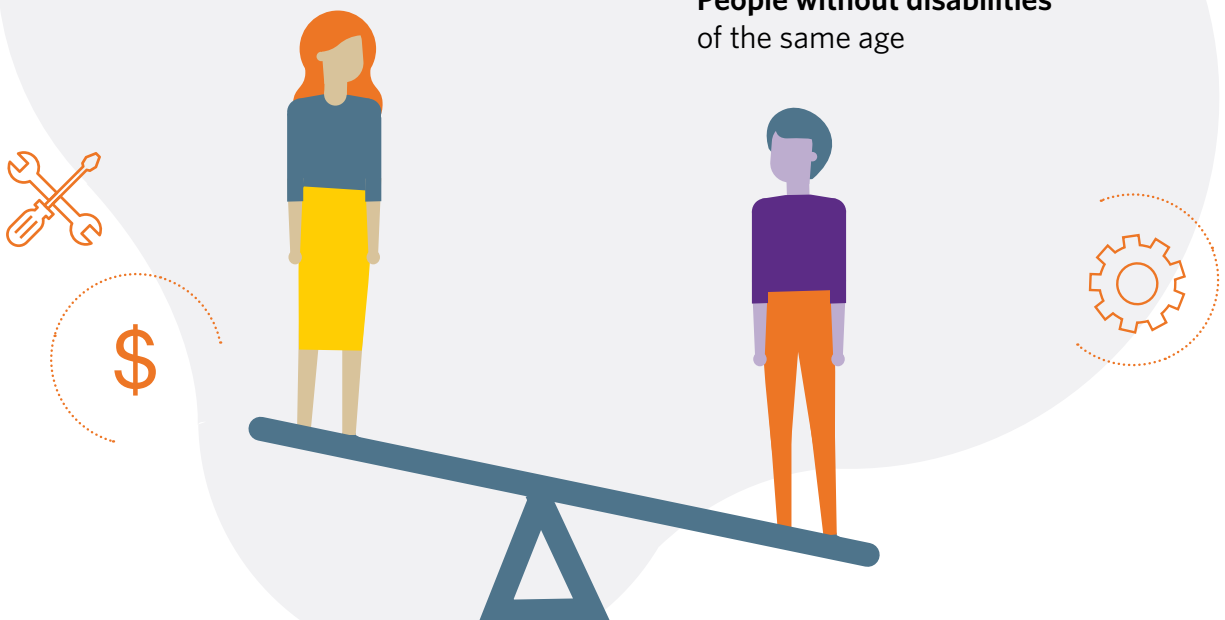
### Labor force participation rate

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

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## 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**

Source: Bureau of Labor Statistics, 2017

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## 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%**

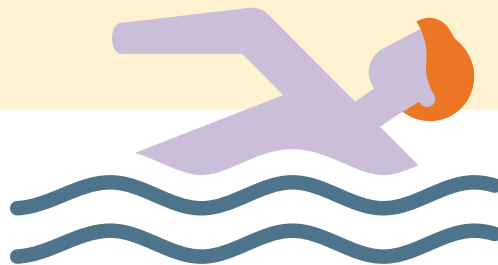
were supported in  
community-based  
non-work setting

Source: StateData: The National Report on Employment Services and Outcomes, 2016

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## 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.



### General health

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%** **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%**

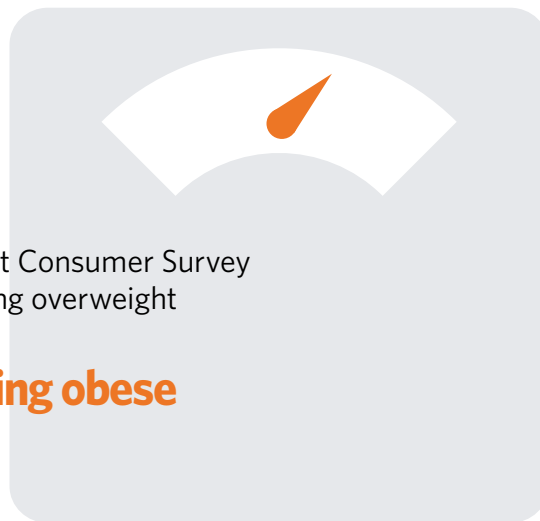
were overweight or obese.

Source: Li, H., 2017

## Obesity

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

**35%** reported being obese



Source: Adult Consumer Survey, 2016-2017 Final Report

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**



Source: Adult Consumer Survey, 2016-2017 Final Report



## 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 (HSRI):



**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%**

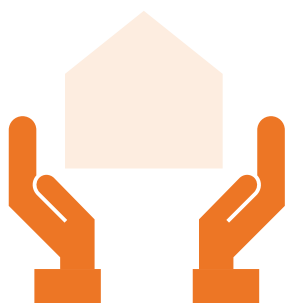
participate in self-advocacy meetings.

Source: Adult Consumer Survey, 2016-2017 Final Report

## 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



**16%**

of individuals lived in the community by themselves or with a roommate in FY 2015

### 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

## 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) than 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:

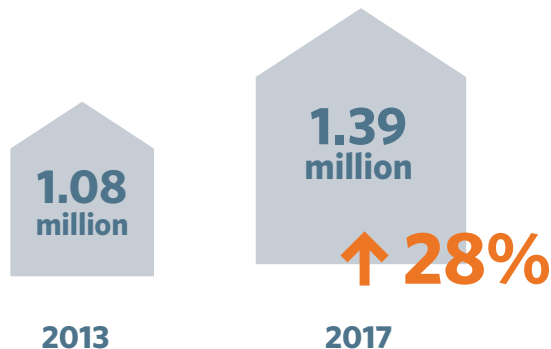
Those that pay more than 40% of their income

### WORST CASE NEEDS:

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

(Source: Schaak et al., 2017)

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



(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.

### Long-term supports

# 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

Source: Larson et al., 2017

## 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: 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.

## 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%**

dealing with  
breakdowns in support



**82%**

are physically  
fatigued



**76%**

meeting work  
responsibilities

Source: Anderson et al., 2018

# 95%

of working FINDS  
participants

## REPORT THAT CAREGIVING HAS HAD SOME IMPACT ON THEIR WORK

### 6 IN 10 PARTICIPANTS

report experiencing three or more of the following  
work impacts from caregiving:

# 43%



taking a leave  
of absence

# 91%



going into work late,  
leaving early, or taking  
time off during the day  
to provide care

# 55%



cutting back  
their hours

# 32%



giving up  
work entirely

# 33%



turning down a  
promotion

# 30%



turning down career  
opportunities in other  
states due to the lack  
of Medicaid portability  
across state lines

# 24%



receiving warnings  
about work attendance  
or performance

### Additional supports needed for caregivers

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**

Source: Perry & Carter-Long, 2016



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

**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

**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



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*For people with intellectual  
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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.

# State & Local Advocacy Data Toolkit

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[Contact your local chapter of The Arc](#)

## Individuals Served by DD Agencies



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

## State spending on services for individuals 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)

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## 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)





