30 Years of
Community Living

for Individuals with Intellectual and/or
Developmental Disabilities (1987-2017)

ACL
Administration for Community Living

The Administration for Community Living has funded three longitudinal data projects of national significance for nearly 30 years. Those projects study where people with intellectual and/or developmental disabilities (ID/DD) live, if and where they work, and how public money is spent on supports. They report on the current status of those supports and on trends over time. This book reviews 30 years of data from state ID/DD agencies about community supports for people with ID/DD.

The Residential Information Systems Project (RISP) is a project of the Institute on Community Integration at University of Minnesota. It studies 1) how many people with ID/DD get paid supports, 2) the types and sizes of the places where people live, 3) how services differ for children and adults, and 4) how services change from year to year. RISP data are used for the Community Living chapter.

StateData.info is a project of ThinkWork! at the Institute for Community Inclusion at UMass Boston. StateData and ThinkWork! describe employment experiences of people with ID/DD and other disabilities, describe policies and supports that lead to employment and other meaningful day activities, and tell personal stories about employment success. StateData research is used in the Employment chapter.

The State of the States in Intellectual and Developmental Disabilities Project is run by the University of Colorado at the Anschutz Medical Campus. It studies 1) how much money is spent on supports for people with ID/DD, 2) how services are funded, and 3) how technology changes people's lives. State of the States data are used in the Expenditures and Technology chapters.

Introduction

> **No one is too disabled to live and work in the community.**
>
> – Nicole LeBlanc

Community living became a reality for many in the last 30 years

Live where you want. Choose who you live with. Earn money at a job you enjoy. Eat when you want. Choose how to spend your free time. Decide how you will spend your money.

These basic personal freedoms are denied to too many people with intellectual and developmental disabilities (ID/DD) who get paid supports.

How many people have ID/DD? How many people get supports and services through state ID/DD agencies? Where do they live and work and at what cost? How can technology make people's lives easier and better? This book tells about the supports people with ID/DD get at home, at work, and in the community. It also tells how supports are paid for.

What is an Intellectual Disability?
What are Developmental Disabilities?

This book describes supports for people with intellectual and/or developmental disabilities. Many people who have an intellectual disability also have developmental disabilities. But not everyone with a developmental disability has an intellectual disability. In this book, ID/DD refers to people with an intellectual disability, developmental disabilities, or both.

People with **developmental disabilities** (DD) may have difficulties with things such as speaking, learning, caring for themselves, moving around, making decisions, living independently, and making and managing money. Their difficulties start before age 22. They continue throughout life, and are severe enough that the person needs on-going supports.

Intellectual disability (ID) begins before age 22. People with ID have trouble learning and solving problems. They also have difficulties with practical skills such as dressing or shopping, social skills such as making and keeping friends and keeping others from hurting them, and with skills such as reading and doing math.

Data Source: Developmental disability was defined in the Developmental Disabilities Act of 2000. Intellectual disability was defined by the American Association on Intellectual and Developmental Disabilities in 2021. States ID/DD agencies may use these or other definitions to decide who is eligible for services.

About 7.38 million people in the U.S. have intellectual and/or developmental disabilities.

7 in 10 people with ID/DD are children
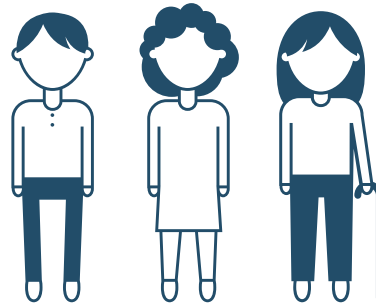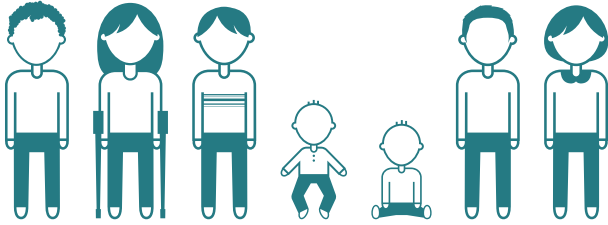
In the United States, about 2.3% of the people have ID/DD. About 7 in 100 children have ID/DD. Some children no longer have significant disabilities by the time they are adults. Fewer than 1 in 100 adults (0.78%) have ID/DD.

Less than 1 in 5 people with ID/DD of all ages (17%) get paid supports.

not receiving supports

receiving supports
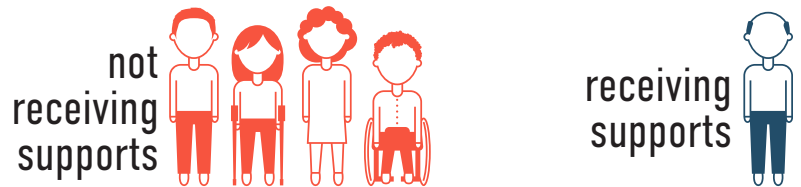
State ID/DD agencies provide publicly funded supports for 1.28 million people with ID/DD.

Most people served by state ID/DD agencies are adults.

62% of people supported by state ID/DD agencies are adults. All children get a free public education, some get supports from public agencies such as child welfare instead of from state ID/DD agencies.

Data Source: RISP

For almost 100 years parents were told to send their children with ID/DD to institutions for care.

Doctors and teachers told parents that institutions were the best place for people with ID/DD to live, learn, and be safe. But many families kept their children at home. Many professionals believed that people with ID/DD could not learn, hold a job, or live with their families.

But institutions were miserable places to live.

Many people entered ID/DD institutions as young children. Most never left. Many got diseases that spread from person to person. Between 1880 and 1967, the number of people living in state ID/DD institutions increased from 2,429 to 194,650. In 1967, almost half of the people in ID/DD institutions were children.
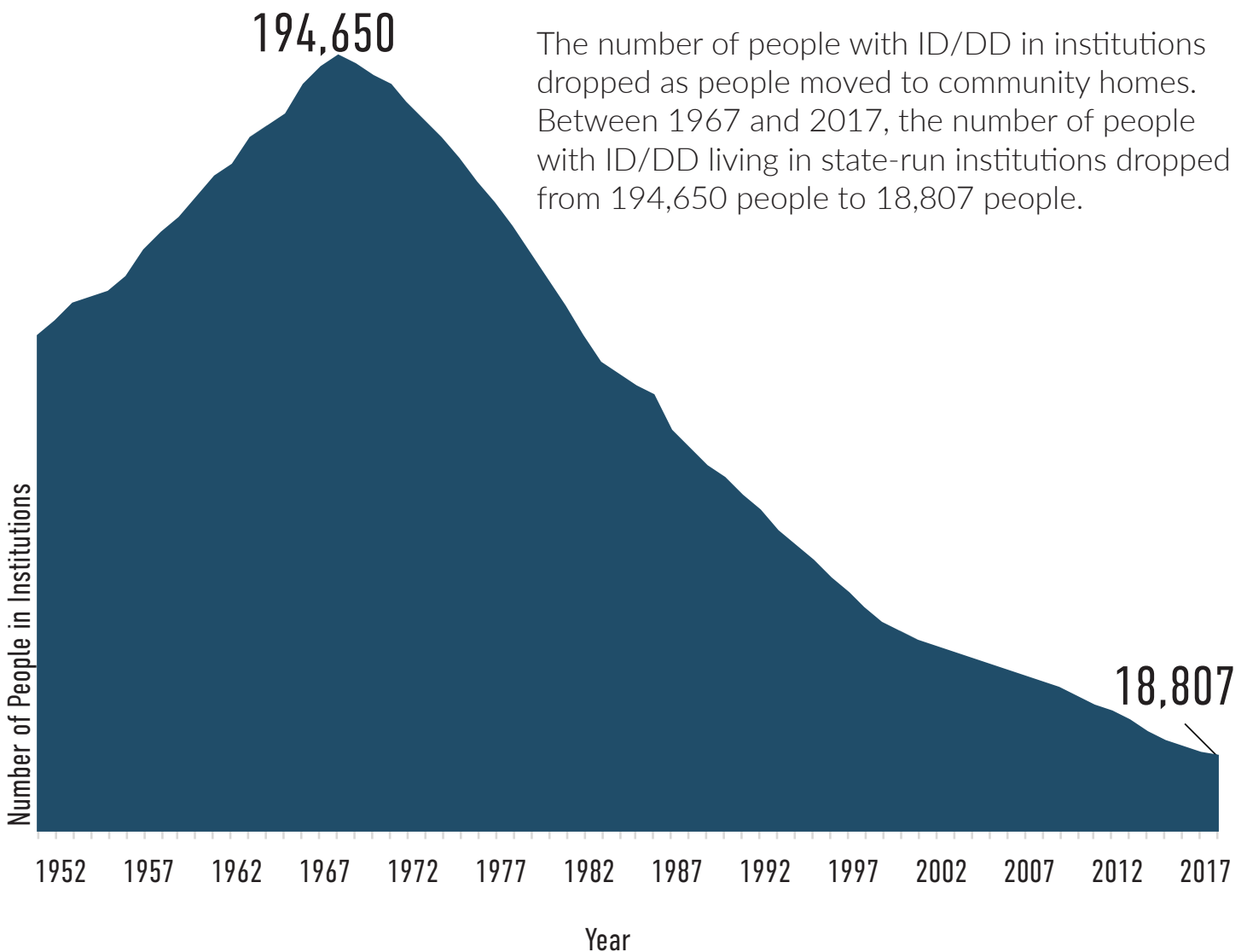
In 1965, Senator Robert F. Kennedy visited Willowbrook State School, one of more than 370 state ID/DD institutions. He called it an overcrowded, filthy, "snake pit." Parents and the public demanded changes.

Institutions started getting smaller and began to close in the 1960s.

In 1963, Congress passed a law (now known as the Developmental Disabilities Act) to improve the lives of people with ID/DD. The Protection and Advocacy System was created to support the legal and civil rights of people with disabilities. In 1971, Medicaid began paying for care in institutions with improved living conditions. Also in 1971, the Supplemental Security Income program began. In 1975, Congress passed a law requiring that a free education be available to all children with disabilities. In 1981, Medicaid dollars became available as an option for states to pay for supports for people living with a family member or in a community home.

The number of people with ID/DD in institutions dropped as people moved to community homes. Between 1967 and 2017, the number of people with ID/DD living in state-run institutions dropped from 194,650 people to 18,807 people.

194,650

18,807

Number of People in Institutions

1952 1957 1962 1967 1972 1977 1982 1987 1992 1997 2002 2007 2012 2017

Year

"Any time you segregate anybody away from the community it's still like being in an institution. An institution is any place you do not have control over your life or make your own decisions."
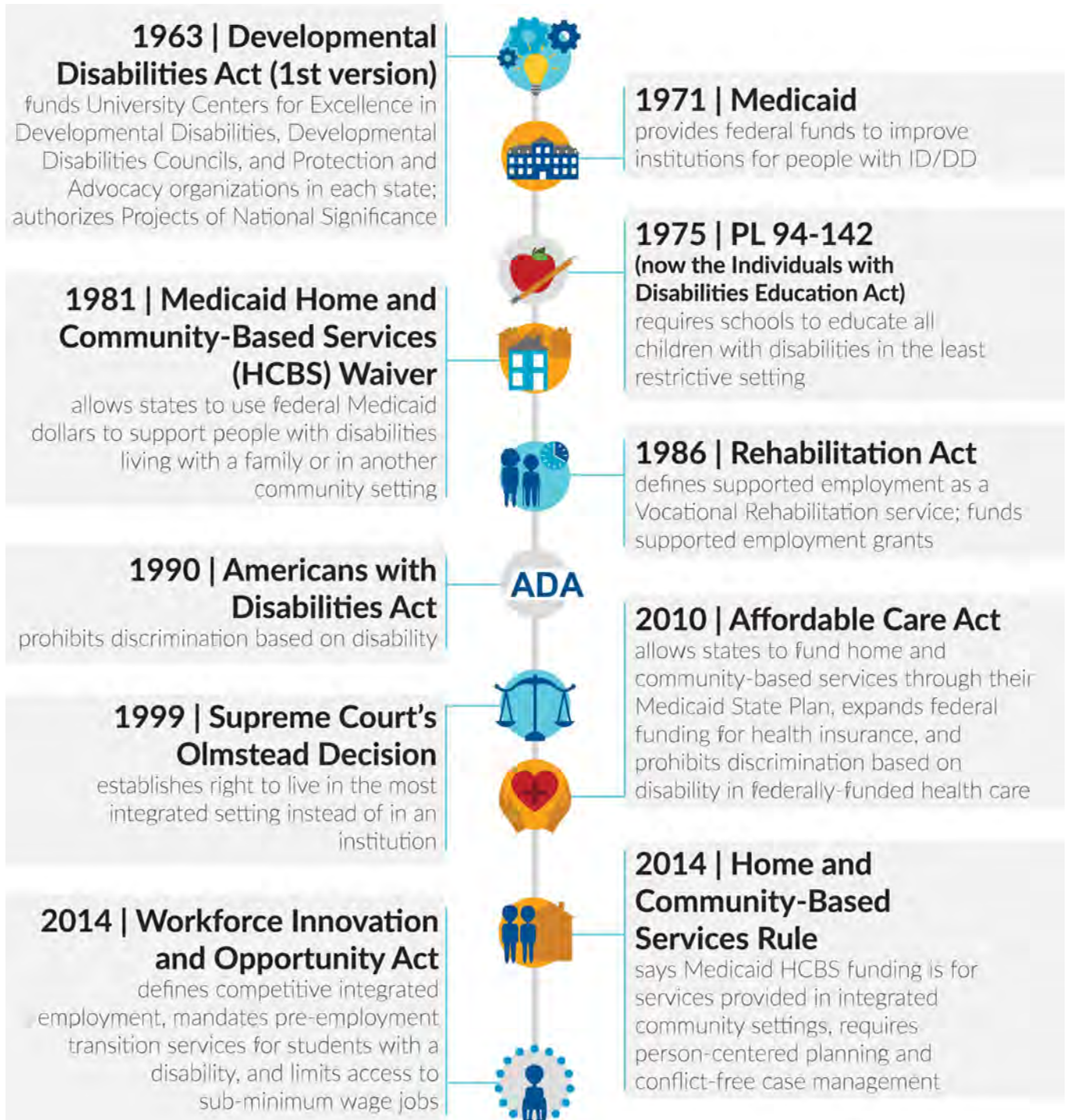
– Tia Nelis

"I went to a place called Grafton State School. I lived there for over 30 years. It was hard work there. We couldn't go places when we were younger. We had to stay mostly on the wards... There was a lot of work scrubbing floors on our hands and knees."

- Helen Bechold

Public policies changed to support community participation.

New laws and public policies made communities more welcoming places for people with ID/DD to live, work and thrive.

1963 | Developmental Disabilities Act (1st version) funds University Centers for Excellence in Developmental Disabilities, Developmental Disabilities Councils, and Protection and Advocacy organizations in each state; authorizes Projects of National Significance

1971 | Medicaid provides federal funds to improve institutions for people with ID/DD

1975 | PL 94-142 (now the Individuals with Disabilities Education Act) requires schools to educate all children with disabilities in the least restrictive setting

1981 | Medicaid Home and Community-Based Services (HCBS) Waiver allows states to use federal Medicaid dollars to support people with disabilities living with a family or in another community setting

1986 | Rehabilitation Act defines supported employment as a Vocational Rehabilitation service; funds supported employment grants

1990 | Americans with Disabilities Act prohibits discrimination based on disability

ADA

2010 | Affordable Care Act allows states to fund home and community-based services through their Medicaid State Plan, expands federal funding for health insurance, and prohibits discrimination based on disability in federally-funded health care

1999 | Supreme Court's Olmstead Decision establishes right to live in the most integrated setting instead of in an institution

2014 | Home and Community-Based Services Rule says Medicaid HCBS funding is for services provided in integrated community settings, requires person-centered planning and conflict-free case management

2014 | Workforce Innovation and Opportunity Act defines competitive integrated employment, mandates pre-employment transition services for students with a disability, and limits access to sub-minimum wage jobs

Communities are better when everyone is included.

Some people want to keep institutions for people with ID/DD open or to create new ones. Research tells us that people with ID/DD who live alone, with their family or with a few other people have more choices, do more in their communities and have better lives than those in institutions. When large groups of people with ID/DD live together, they have fewer choices about their schedule, meals, and activities. Most adults with ID/DD want to choose the people they live with. Many want to live in homes of their own.

Being included means living and working with family, friends and neighbors.

People with ID/DD want to work. But most spend their days at home or in a day program. Few have jobs earning minimum wage or more. Few work in integrated community settings.

Working gives people money to buy things and do things they enjoy. It helps them learn new skills and meet new people. It provides a place away from home to do something important.

EMPLOYMENT...

connects people
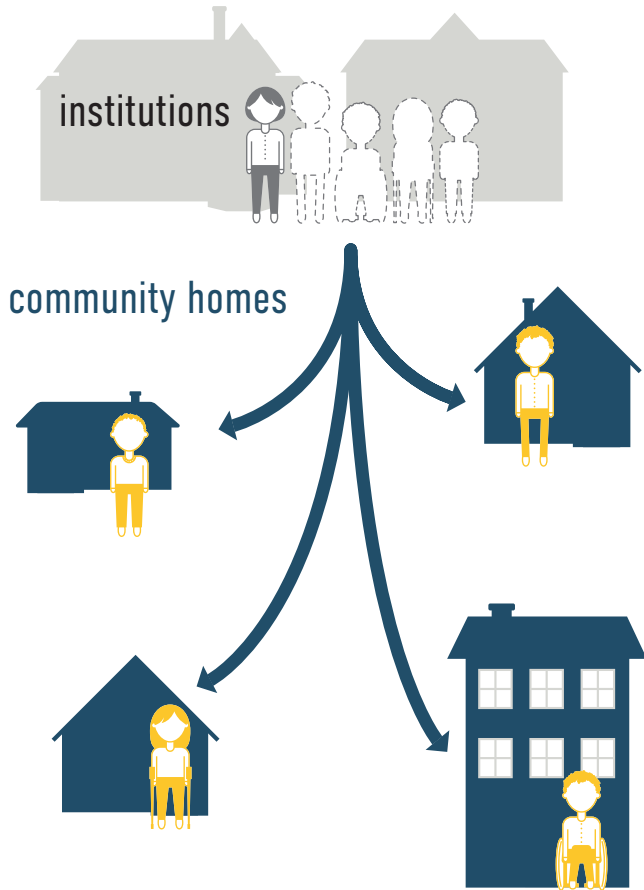
is a path to opportunity

means equity
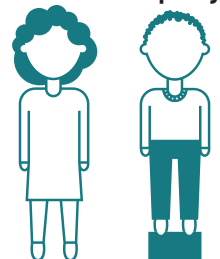
Between 1987 and 2017 life got better for many people with ID/DD.

1. Four of every five people with ID/DD who lived in an institution in 1987 moved to a community home by 2017.

institutions

community homes

2. Medicaid spending on people with ID/DD increased by three and a half times (from $15.7 billion to $55.3 billion in 2017 dollars).

$15.7 billion

$55.3 billion

1987

2017
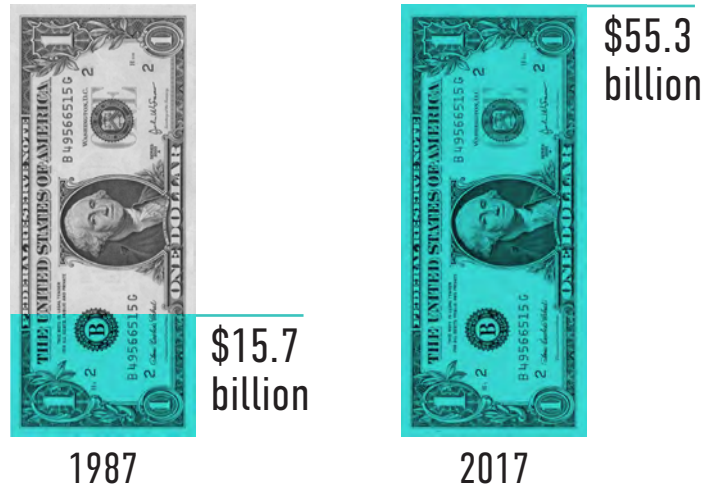
3. The number of people with ID/DD supported to work in community jobs increased from 33,000 to 135,000.

1987   33,000

2017   135,000
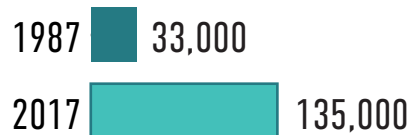
4. The number of people with ID/DD getting Medicaid-funded supports in home and community-based settings exploded from 22,869 people to 860,500 people.

1987   22,869

2017   860,500

Data Sources: 1 - RISP, 2 - SOS, 3 - ThinkWork!, 4 - RISP

People who live in different states have different opportunities.

Each state makes different choices about how to use tax dollars to pay for supports for people with ID/DD. Some states collect very little in taxes while others collect more. The amount of money spent on supports for people with ID/DD is different in each state.

In some states, nearly everyone with ID/DD who get supports lives with a family member. In other states, most adults with ID/DD who get supports live in their own home or in small group settings. In some states, most adults with ID/DD getting supports work in a community job. In other states, very few people with ID/DD get supports to work in community jobs.

> **People with disabilities deserve to live in the community without being segregated. When we are included, people see what we have to offer.**
>
> - Max Barrows

Living in the Community

Amy and her brother

Living a Dream

Amy lived with her family until she was 23 years old. After living in a group home for three years, she wanted more.

"I moved into my own apartment right before Halloween [in October]. It's awesome. I love it," she says. Some changes were made to her apartment so it was accessible, allowing her to live alone.

"The staff come when I need them to. I just call on my cell phone." She got a landline to avoid using up her mobile phone minutes. "Which I already did," Amy quips. Like all young people, she learned from a few early mistakes.

Amy's mother worried about Amy feeling isolated living alone, but that hasn't been a problem. "What I like best is going to see my friends when I want to and I can come here when I want peace and quiet," Amy said.

Amy works full time, doing packaging and assembly work, and enjoys it. She now feels ready to try something more challenging. "I can see myself doing something a little bit more independently," she says.

Amy is thinking about marrying her boyfriend – a dream her mother thought would never happen. "In the last year she was at home she was very anxious to [move out]," her mother said. We learned that "You have to do your homework and find a good provider. It doesn't happen automatically," she said, but "with perseverance, high expectations for full adult lives…, and talking with other parents, it can happen."

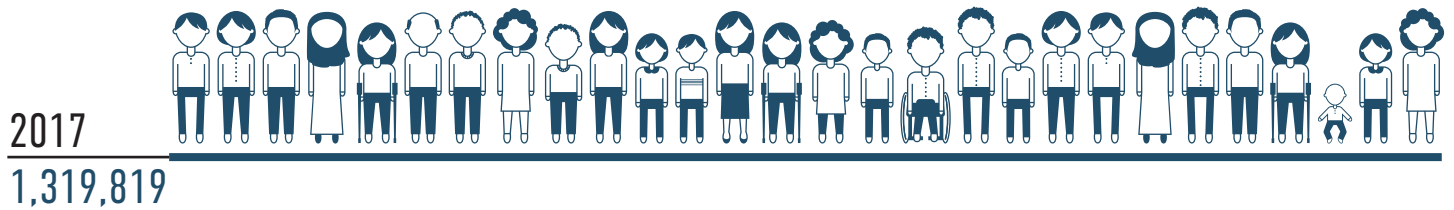# Most people with ID/DD live with family members for their whole life. Only some get funded supports.

In 2017, of the people getting funded supports, 58% lived with a family member, 12% lived in their own home, 5% lived with a host or foster family, 16% lived in a group home shared by six or fewer people, and 9% lived in an institution of seven or more people (5% lived in an institution with 16 or more people).

9%

Institution | a residence of seven or more people owned, rented, or managed by the organization or agency that provides services to people in the facility

16%

Group Home | a residence of six or fewer people owned, rented or managed by the organization or agency that provides services to the people in the home

58%

Family Home | a residence shared by a person with ID/DD and their related family members.

5%

Host or Foster Family Home | a home owned or rented by an individual or family that provides supportive services to one or more people with ID/DD

12%

Own Home | a home owned or rented by one or more adults with ID/DD

The number of people with ID/DD getting paid supports doubled between 1998 and 2017.

1998
693,691

As the Medicaid Home and Community-Based Supports Waiver program got bigger, many more people with ID/DD were able to get paid supports.

2017
1,319,819

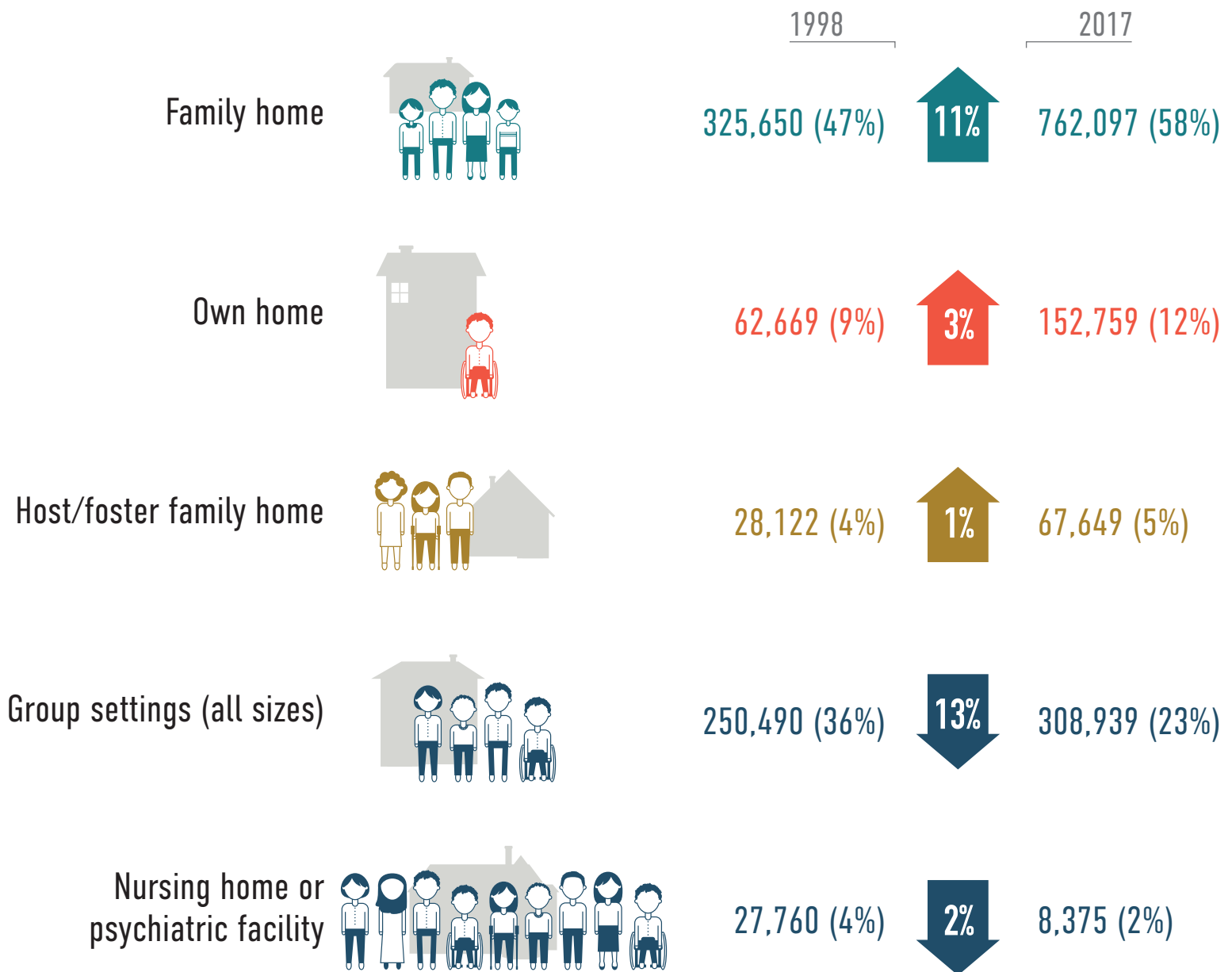# Among people with ID/DD getting supports, children are much more likely than adults to live with a family member.

85% of children lived with a family member

42% of adults lived with a family member

By 2017, only 1 in 4 people with ID/DD who got supports lived in a group setting.

Between 1998 and 2017, the percentage of people getting support who lived with a family member went up from 47% to 58%. The percentage living in their own home went up from 9% to 12%. The percentage living with a host or foster family went up from 4% to 5%. The percentage living in a group home or ID/DD institution went down from 36% to 23%. The percentage living in a nursing home or psychiatric facility went down from 4% to 2%.

		1998		2017
Family home		325,650 (47%)	11% ↑	762,097 (58%)
Own home		62,669 (9%)	3% ↑	152,759 (12%)
Host/foster family home		28,122 (4%)	1% ↑	67,649 (5%)
Group settings (all sizes)		250,490 (36%)	13% ↓	308,939 (23%)
Nursing home or psychiatric facility		27,760 (4%)	2% ↓	8,375 (2%)

The number of people getting supports who did not live with a family member doubled.

The number of people with ID/DD getting paid support who did not live with a family member increased from 255,673 to 516,505 between 1987 and 2017.

1987
255,673 people
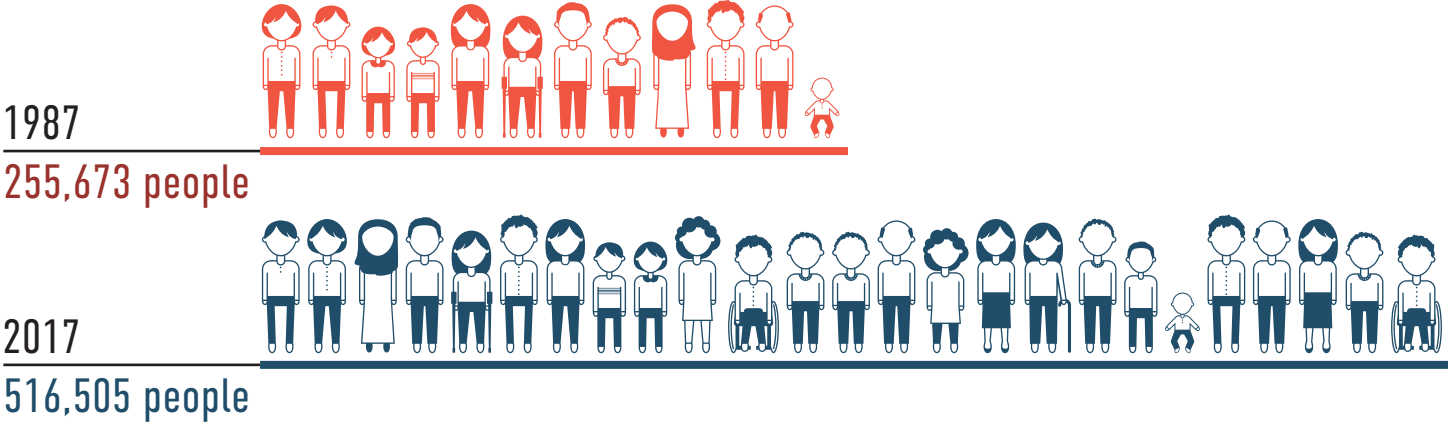
2017
516,505 people

By 2017, most people with ID/DD <u>not</u> living with a family member shared a home with 6 or fewer people with ID/DD.

The percentage of people with ID/DD <u>not</u> living with a family member who lived in homes shared by six or fewer people with ID/DD increased from 1 in 4 (27 percent) in 1987 to 4 in 5 (83 percent) in 2017. The number of people with ID/DD living in homes shared by six or fewer people with ID/DD grew from 69,933 in 1998 to 427,947 in 2017.
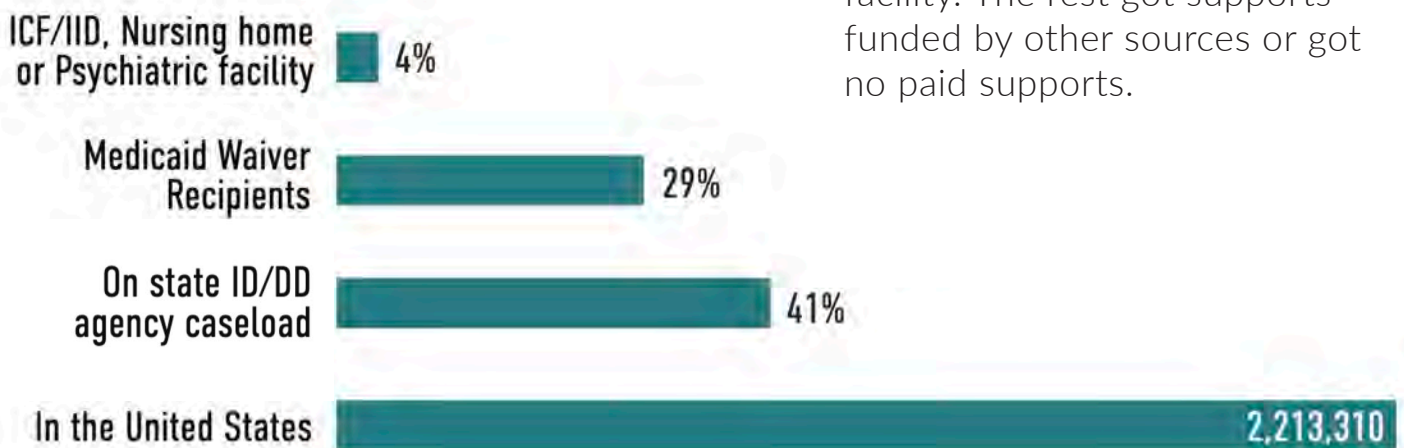

	1998		2017
6 or fewer people	69,933 (27%)	↑ 56%	427,947 (83%)
7-15 people	48,637 (19%)	↓ 9%	51,822 (10%)
16 or more people	137,103 (54%)	↓ 47%	36,736 (7%)
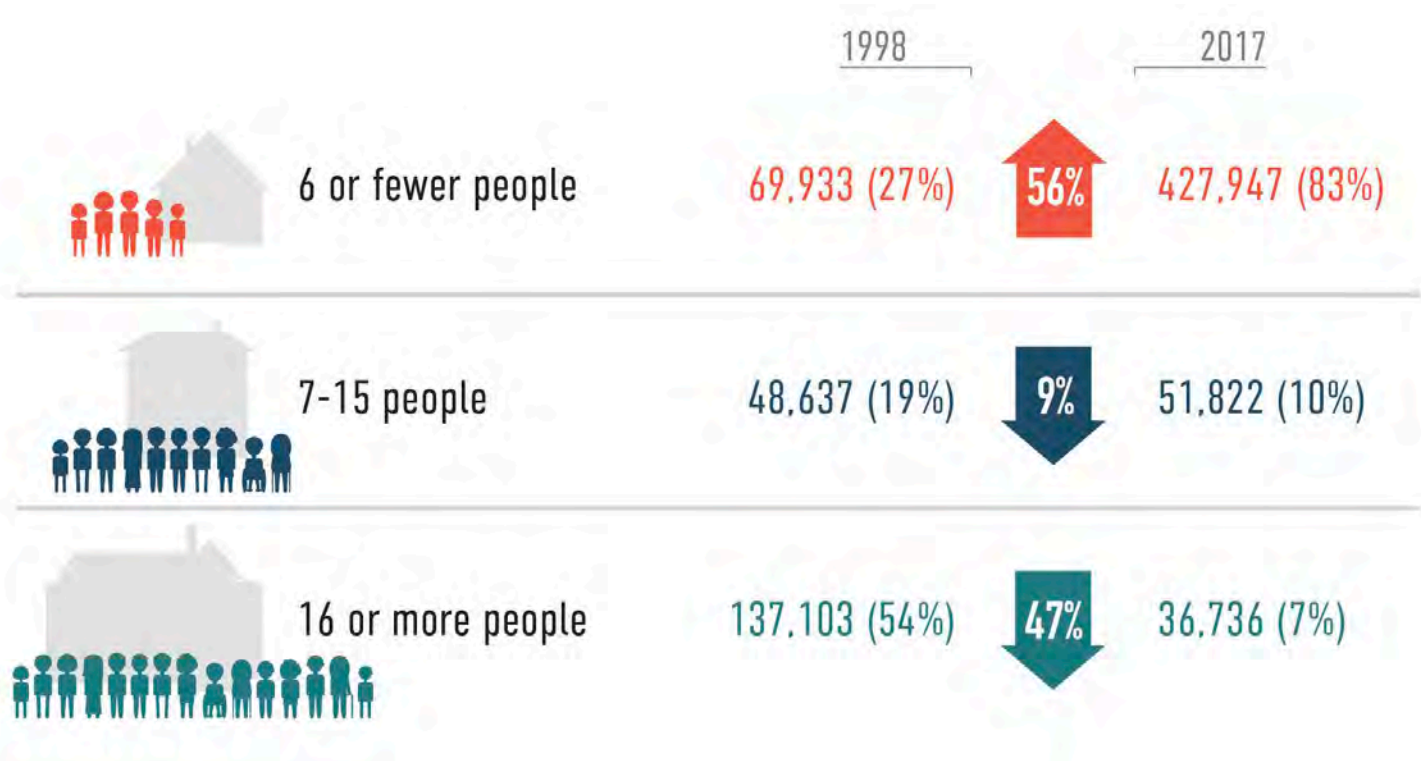
In 1987, 9 of 10 people with ID/DD getting Medicaid-funded supports lived in an institution. Today, 9 of 10 people getting Medicaid-funded supports live in the community.

The number of people with ID/DD living in a Medicaid Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) dropped from 145,162 in 1987 to 73,856 in 2017. The number of people with ID/DD getting Medicaid Home and Community-Based Supports (HCBS) Waiver funding increased from 22,689 to 860,500.

860,500 HCBS

Community

145,162

22,689

Institution

73,856 ICF/IID

1987   1997   2007   2017
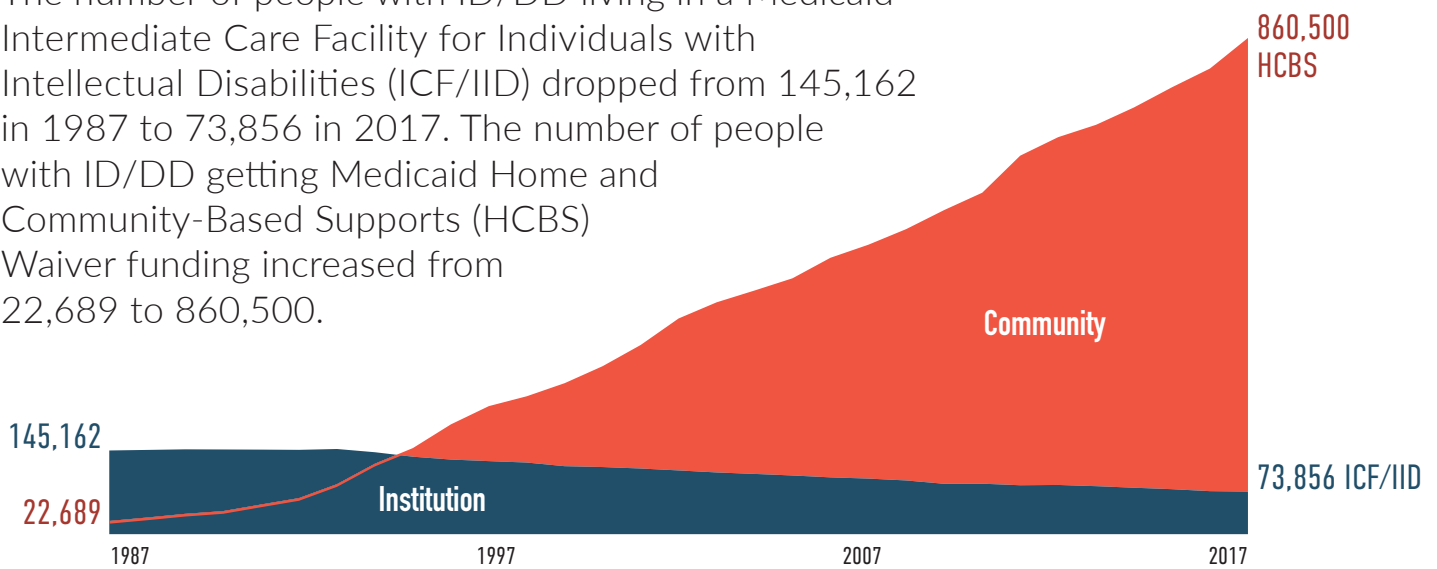
Most adults with ID/DD do not get services from state ID/DD agencies.

About 2.2 million adults in the United States had ID/DD. About 4 in 10 were on ID/DD agency caseloads. About 3 in 10 got Medicaid HCBS funding. But only 4 in 100 lived in an ICF/IID, a nursing home, or a psychiatric facility. The rest got supports funded by other sources or got no paid supports.

ICF/IID, Nursing home or Psychiatric facility — 4%

Medicaid Waiver Recipients — 29%

On state ID/DD agency caseload — 41%

In the United States — 2,213,310

By 2017, 17 states had closed all of their large state-run institutions for people with ID/DD.

The number of state-run ID/DD institutions went from 224 in 1987 to 119 in 2017. Between 2015 and 2020, an average of 8 state-run institutions closed each year. States with no state-run institutions for people with ID/DD in 2017 were Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Maine, Michigan, Minnesota, Montana, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont and West Virginia.

But, 103,983 people with ID/DD still lived in nursing homes, psychiatric facilities, or group facilities shared by 7 or more people with ID/DD in 2017.

no open facilities

1 open facility

2-5 open facilities

6 or more open facilities

Community Employment

> **I don't just work to have a job, I work to live.**
>
> - Ashley Wolfe

Maggie's Story

Maggie works as an office manager's assistant at AMP Agency. AMP helps well-known businesses like Hasbro, Princess Cruises, Samsung, and Boden with their marketing. Maggie, together with her employment specialist and AMP's Office Manager, carved out a job that interested her and benefited AMP.

Maggie had a part-time job in a bakery, but she wanted a job doing office tasks for an interesting company. With help from her employment specialist, Maggie began looking for these type of jobs. This was how she found out about the opportunity at AMP.

Maggie is a fast learner who enjoys working in the creative environment at AMP. She works at AMP four hours a day, three days a week and has another part time job at a grocery store. The managers are happy with Maggie's punctuality, positive attitude, and work ethic. Maggie accomplishes many important tasks at AMP and her coworkers can't imagine the company without her.

At AMP, Maggie enters contact information from clients' business cards into a computer. She also sends and receives packages and other mail, makes copies, shreds paper, stocks supplies, makes coffee, and keeps the kitchen and conference rooms clean.

Maggie's duties are organized so that she does all her kitchen tasks at a certain time, office tasks at another time, and supplying tasks at another time. This way, people know when Maggie will be working in each area. However, tasks may be more or less important, depending on the day. So Maggie has to pay attention to the tweaks that her employment specialist makes to her task list.
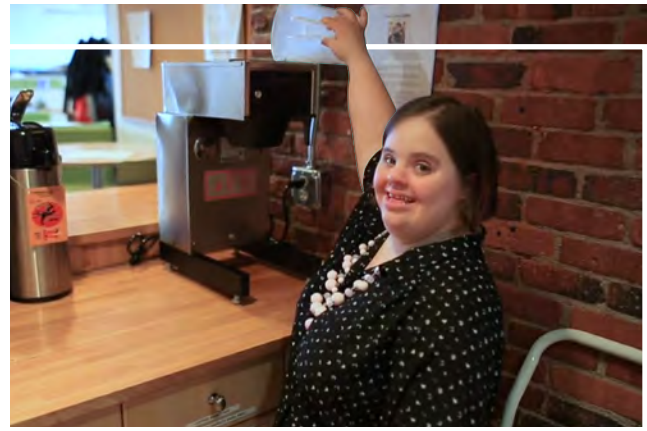
Maggie at work

Jobs are an important part of life.

Working allows us to contribute to our communities. Having a job means we have our own money. Having money allows us to make choices about things that are important. Jobs also give us purpose, help us build skills, and provide a pathway to connect with others.
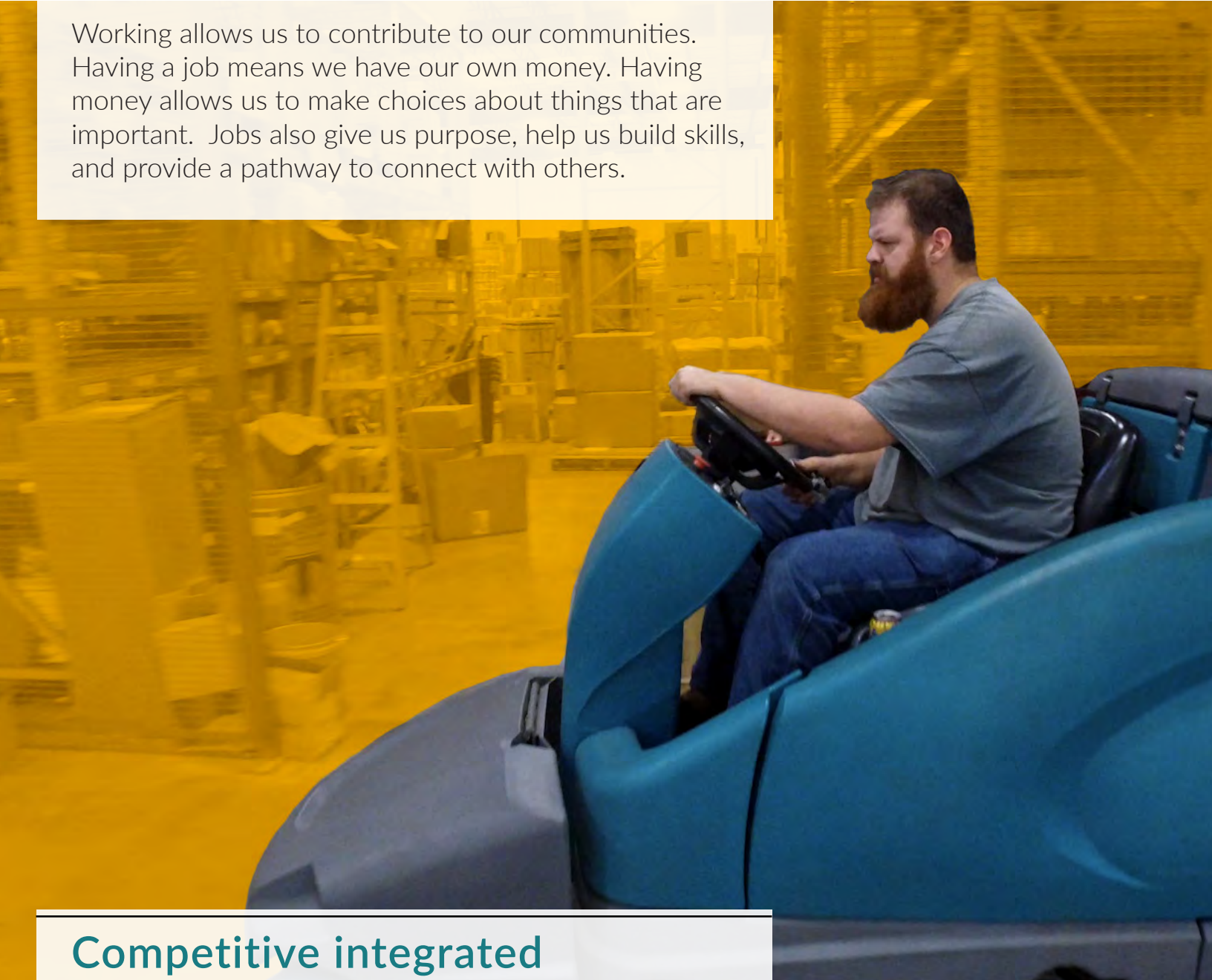
Competitive integrated employment is the term used to describe a good job.

In a **competitive integrated job**, a person works for a local business, earning a regular wage alongside coworkers who do not have disabilities. The person may get help to find or keep the job, but the business they work for is not paid to provide supports to the person.

It is important to be part of your community when you are not working.

Community life engagement is being part of your community when you are not working. This may include volunteering, taking classes, going to religious activities, going to the gym, or doing other activities people with and without disabilities do together when they are not working. Sometimes people get paid supports to help them plan and get to these activities.

Some people spend their day in activities that are more like programs than jobs.

Some people with ID/DD have jobs that are not integrated in the community. These jobs often pay less than minimum wage, and most of the workers have a disability. Often the person with the disability receives their paycheck from the organization that is paid to help them. Sometimes these programs are called sheltered workshops.

People are not fully part of their community when:

1. Their job pays less than minimum wage.

2. Most coworkers have a disability.

3. The employer is also paid to provide supports.

4. Activities are chosen because the group is going.

5. Everyone doing the activity gets supports.

6. You go places without knowing why.

"Not being part of the community is a human rights issue."

- Max Barrows
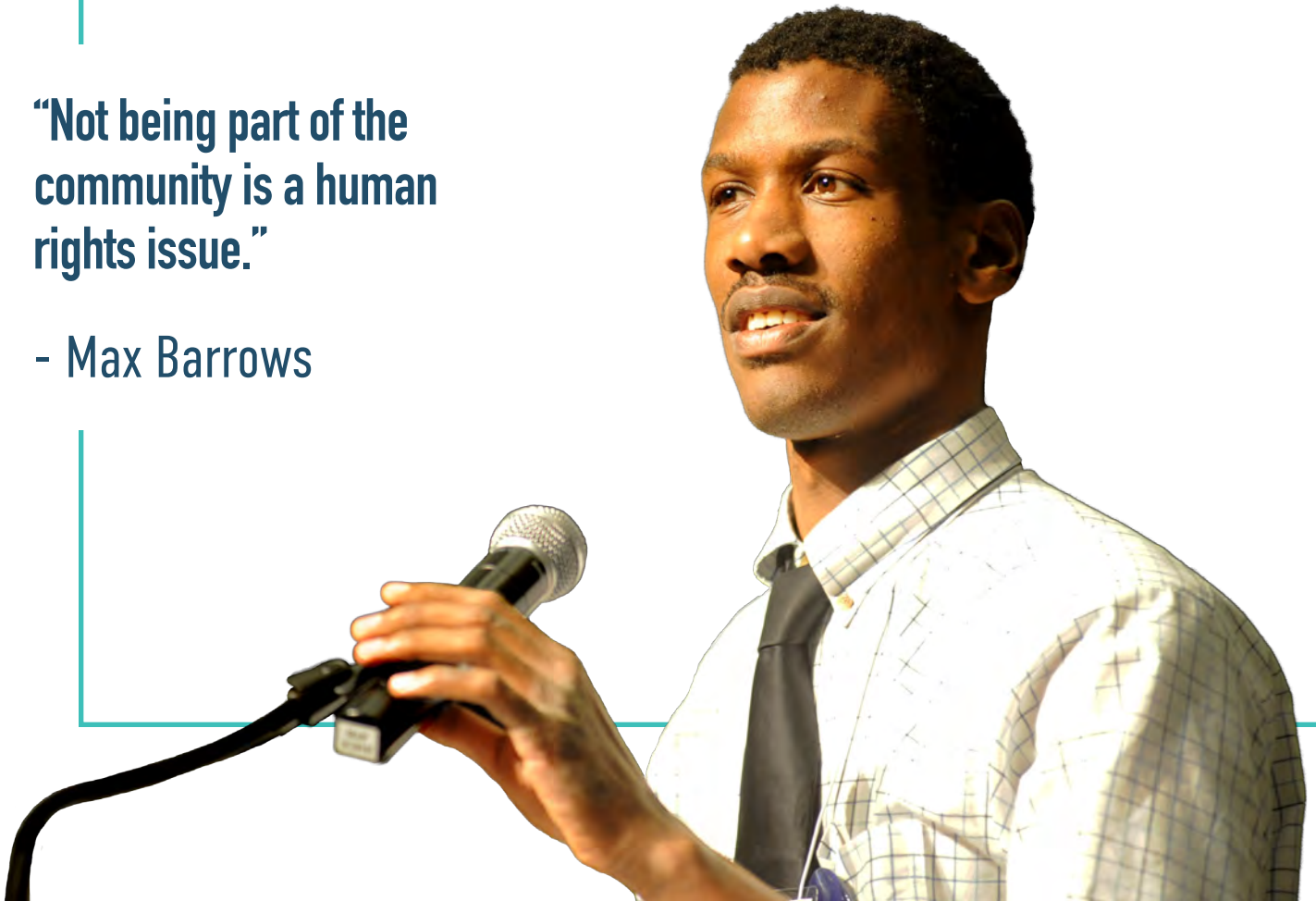
Only 1 person in 5 getting employment or day services from a state ID/DD agency gets support to work in an integrated job.

Of the 641,608 people with ID/DD who got any employment or day service in 2017, only 130,402 got integrated employment services.

Data Source: ThinkWork! IDD Survey, 2017

any employment or day service **641,608**

integrated employment service **130,402**

Many people with ID/DD want to work but do not have a job.

Research shows us that people with ID/DD want community jobs but do not get help to make this happen. Only 1 in 5 people with ID/DD have a paid, integrated job. Listening to people means helping those who want to work to find a job.

Do not have a job

Have a job

8 out of 10 people (80%) with ID/DD do not have a paid job in the community.

Want a job

Don't want a job

4 of those 8 people (48%) want a job in the community

Have goal

No goal

Of those 4, fewer than 2 people (40%) have a goal to get a job in the community documented in their Individualized Service Plan
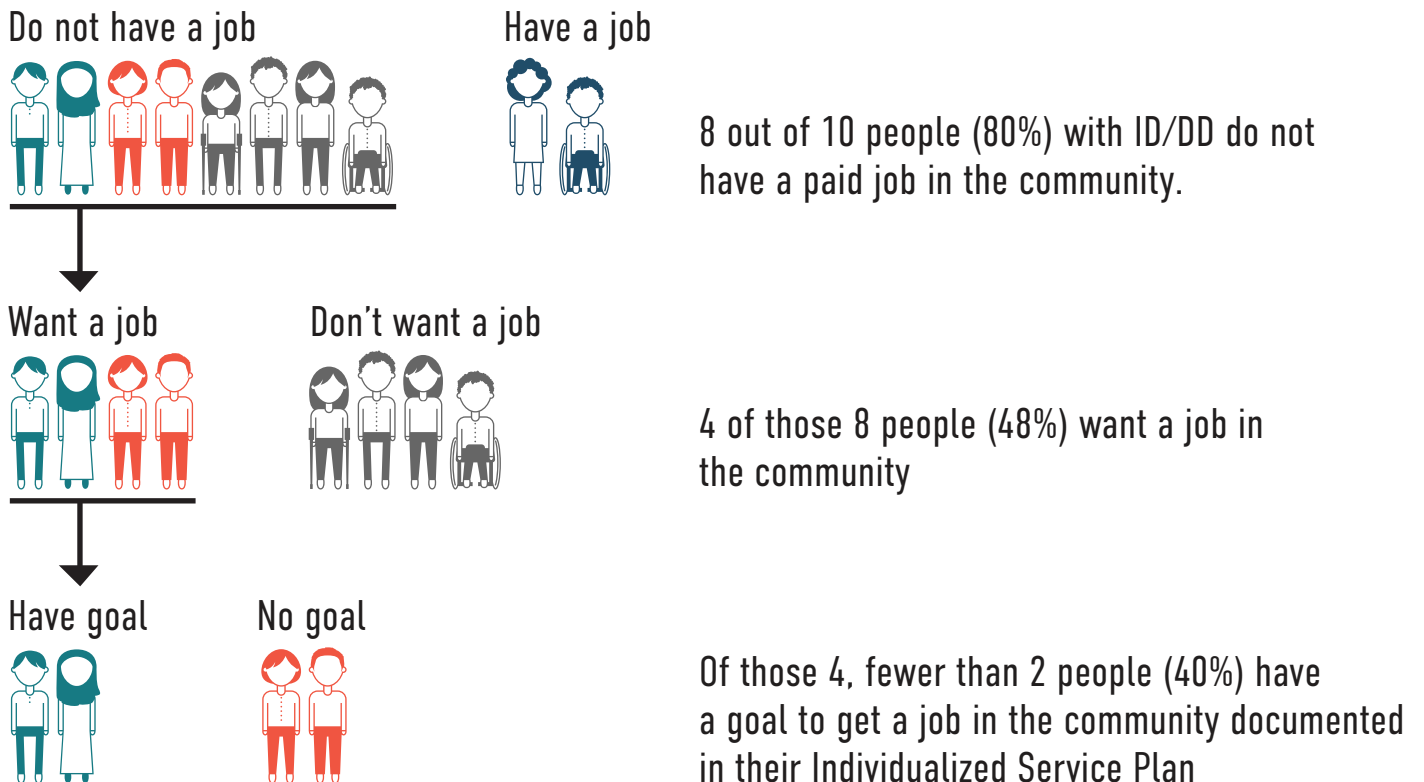
Data Source: National Core Indicators, 2017

Most people with paid, integrated jobs have an individual job but some work in small groups of people with disabilities.

About 75% of people worked in an individual job, and 25% worked in a small group job often called a mobile work crew or enclave. Small group jobs are in the community and can be part of a short-term pathway to employment, but are not competitive integrated jobs and they may pay less than minimum wage.

group supported job

25%
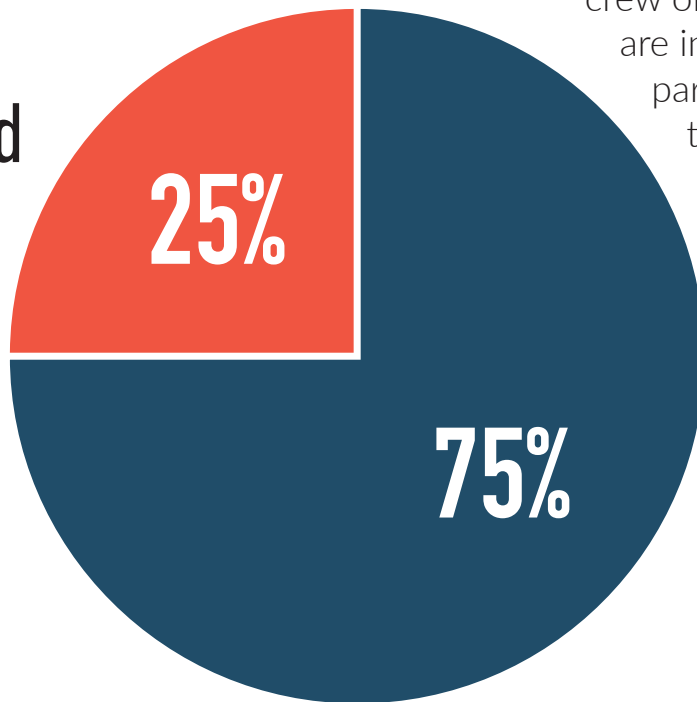
75% individual job

People with individual jobs work more hours and earn more money.

People in individual jobs worked an average of 13 hours, and earned about $117 per week ($8.90 per hour). People in group jobs worked an average of 12 hours and earned about $70 per week ($5.60 per hour). People need help to find jobs that pay at least minimum wage and offer more hours.

$70 per week

$117 per week

Group job
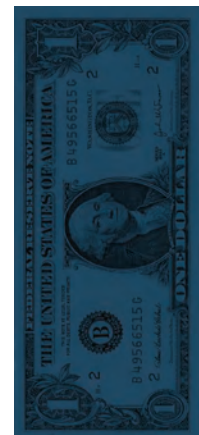
Individual job

Data Source: National Core Indicators, 2017

Integrated employment is increasing and sheltered work is decreasing. However, most people do not have community jobs.

Between 1990 and 2017, the number of adults with ID/DD in employment or day supports grew. The number of people in integrated employment grew from a few thousand to nearly 150,000. The number of people working in sheltered workshops went down, especially in the last few years.

The number of people getting day supports grew the most. Day supports are sometimes called non-work supports. When people are getting day supports they do not earn money. Day support activities can take place in program settings or in the community. Typically, people with ID/DD getting day supports are grouped together because of their disability instead of by their common interests or goals.

total 641,608

non-work

facility-based work

integrated employment

Number of People

700,000

600,000

500,000

400,000

300,000

200,000

100,000

0

1990   1996   2004   2012   2018

Year
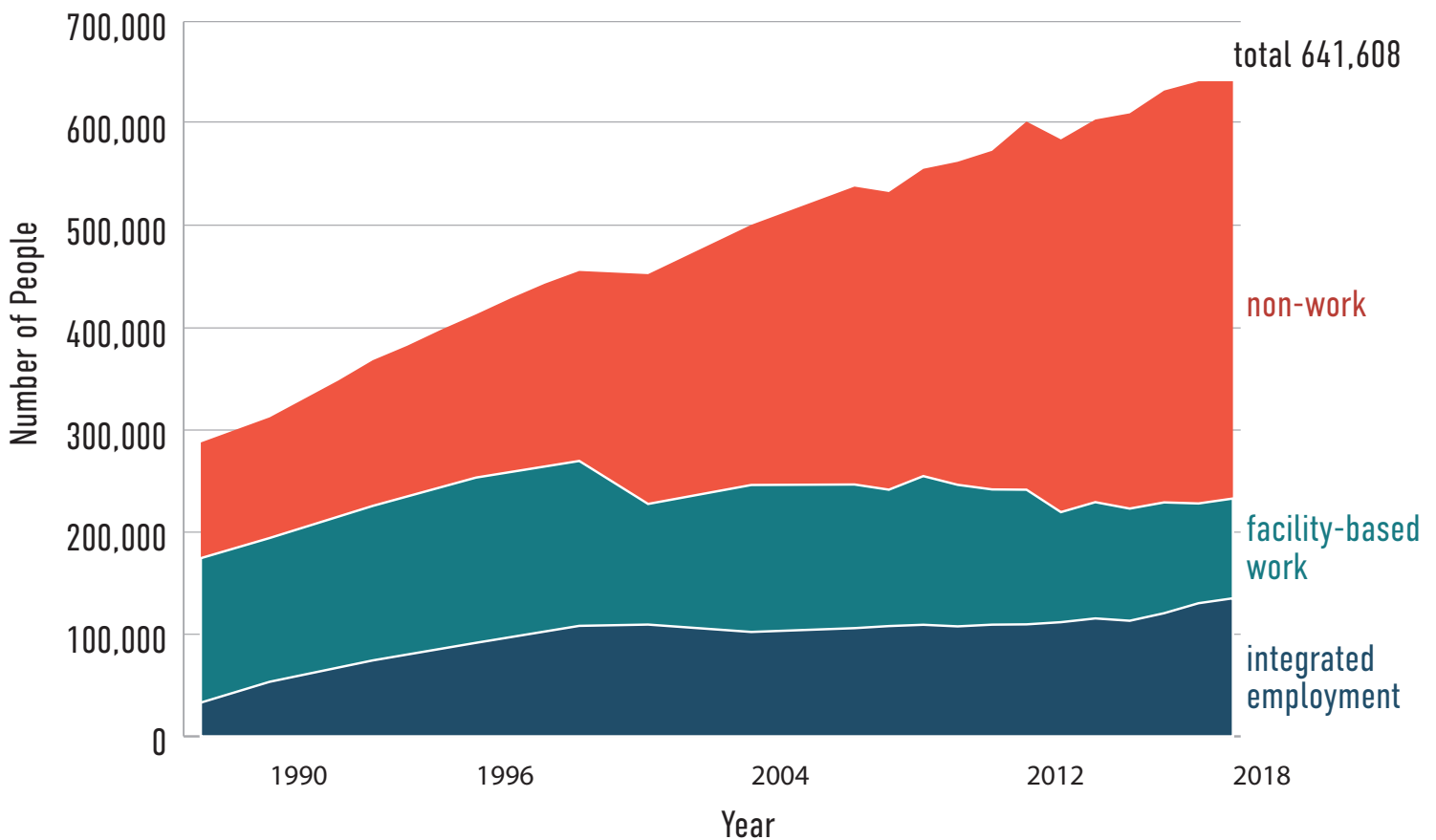
Data Source: ThinkWork! IDD Survey, 2017

Participation in integrated employment varies by state.

The state where you live matters. Nationally, about 1 of 5 people with ID/DD who get an employment or day service are supported to find or keep a community job. But the number varies by state, from fewer than 1 in 50 people to 43 in 50 people.

State ID/DD agencies' policies have a strong impact on whether or not someone gets supports to help them find and keep a community job.

The good news is that we know the changes that state ID/DD agencies can make to support more people to work in the community.

Percent of people in integrated employment by state
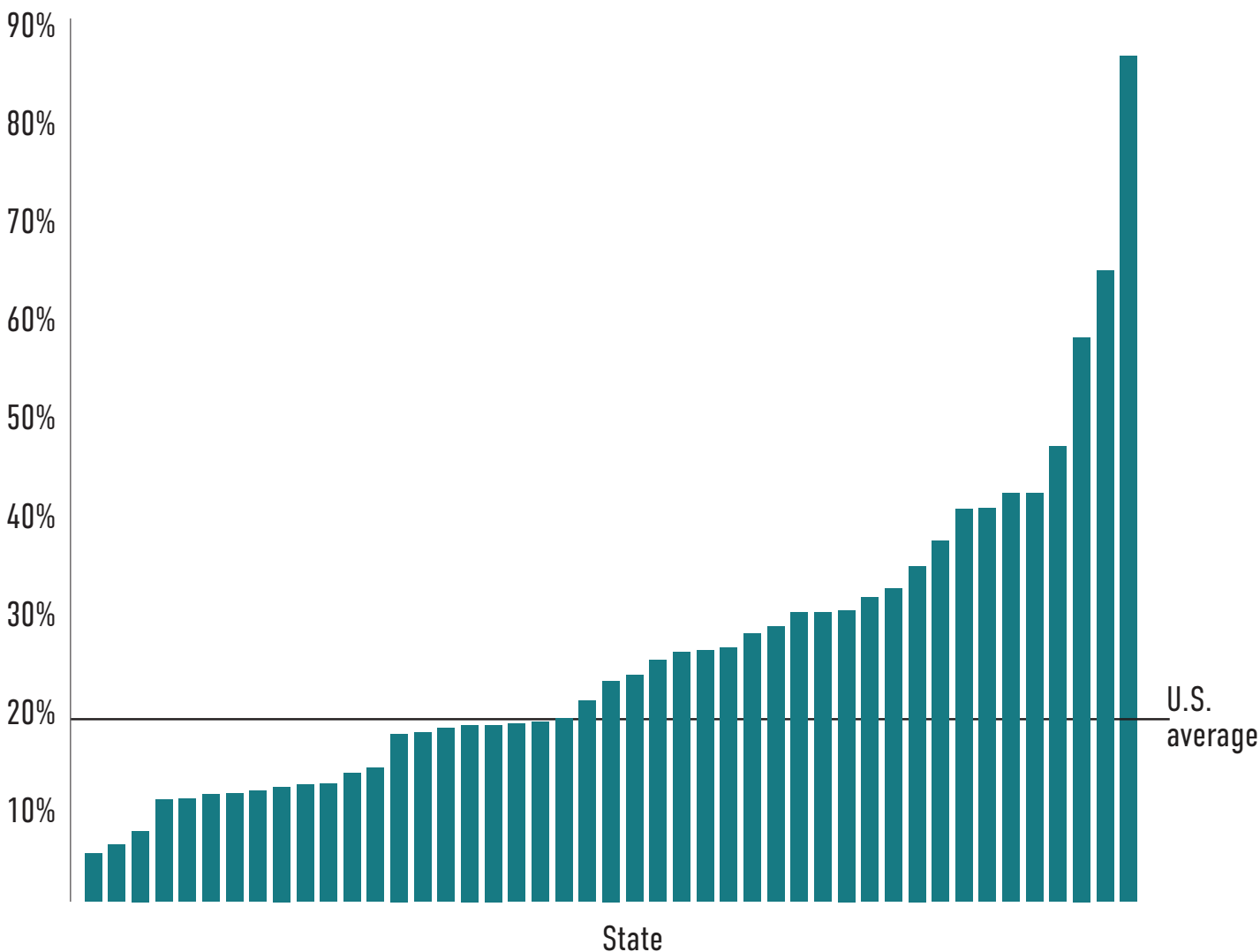
Data Source: ThinkWork! IDD Survey, 2017

State policies about employment make a difference.

Employment First means that employment in community jobs should be the first option for individuals with ID/DD. All citizens, including people with significant disabilities, can participate in integrated employment and earn real wages.

States with **Employment First** policies support employment as the goal for young adults leaving school and adults needing employment or day support. People with disabilities living in those states are more likely to have integrated community jobs.

"Employment First means people with disabilities, people of all abilities, need to have a purpose in life. We all have amazing potential to pursue a purpose in life if given the opportunity. Employment First is about making that your top tier goal in life and really striving to get a job and be a part of your community."

– John Fenley,
   People First of
   New Hampshire

States that support more people to work in integrated jobs have clear policies and strategies that support work.

More people with ID/DD have jobs in states that make employment a priority. Those states focus on supporting integrated jobs in policy, services, funding, training and capacity building, and outcome measurement. We call these states **high performing states**. In **high performing states**, agencies like Vocational Rehabilitation and Education partner with ID/DD agencies to get better results. **High performing states** also have leaders who value integrated employment.

The High Performing States Model

Catalysts

leadership

values

Strategy

Policy & goals

Financing

Training & TA

Service innovation

Outcome data

Integrated Jobs

INTERAGENCY COLLABORATION

Hall et al, 2007

“ Put your money where your mouth is. Are you going to invest or not? ”

- Julian Wang

Expenditures

Amy's Story

Fear gripped Amy Grimm's family when they heard the 2012 announcement that the Northern Virginia Training Center (NVTC) would close in 2016. NVTC had been Amy's home since 1975. Her family felt it was the only place she could live safely due to her support needs.

In 2016, after planning and preparation with The Arc of Greater Prince William County, Amy moved into a home with three roommates near her family using funding from Virginia's Community Living Waiver.

Her family's fear, anxiety and terror slowly turned into relief and confidence. "Her life opened up completely once she moved," says her sister, Laurie. "She loves having her own room, is proud of her house, she has had dates, uses an iPad, goes to shows, movies, and loves shopping every week." Waiver funding also supports Amy's day program where she does art and music therapy.

Amy attends family events and other community parties that were rarely possible when she was at NVTC. "Living in the community has been awesome for Amy," says Laurie. "Her life has improved more than I ever thought was possible and every day I am grateful for the wonderful staff and all the opportunities she has now."

Spending for individuals with intellectual and/or developmental disabilities increased over time.

Researchers studying how public money is spent to support people with ID/DD report that since 1977, total adjusted spending increased every year except for 2011 and 2014. Total spending was highest in fiscal year 2017 at $71.7 billion dollars.
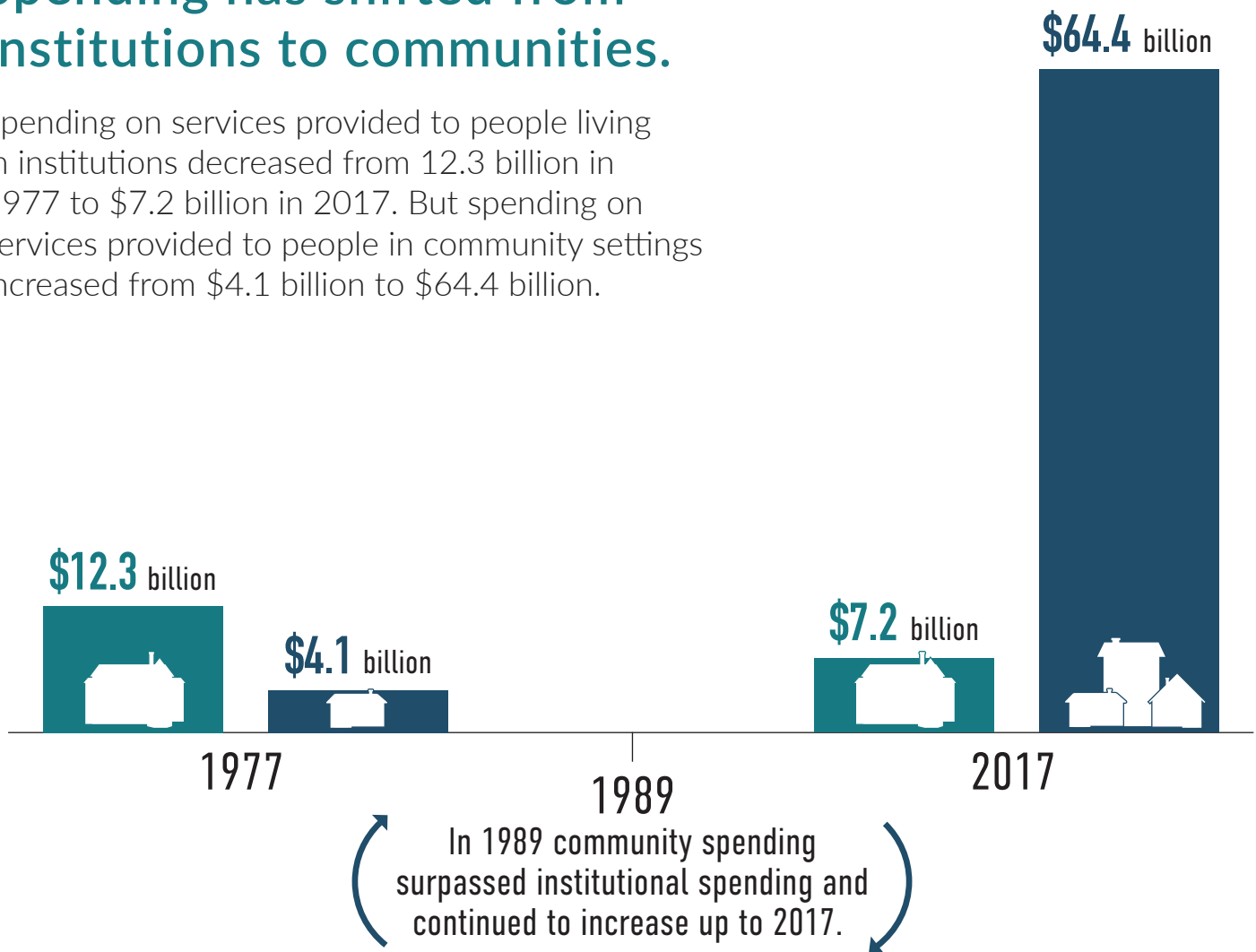
Total ID/DD Public Spending

Fiscal Year	Spending
1977	$16.4 billion
1987	$27.4 billion
1997	$44.5 billion
2007	$59.9 billion
2017	$71.7 billion
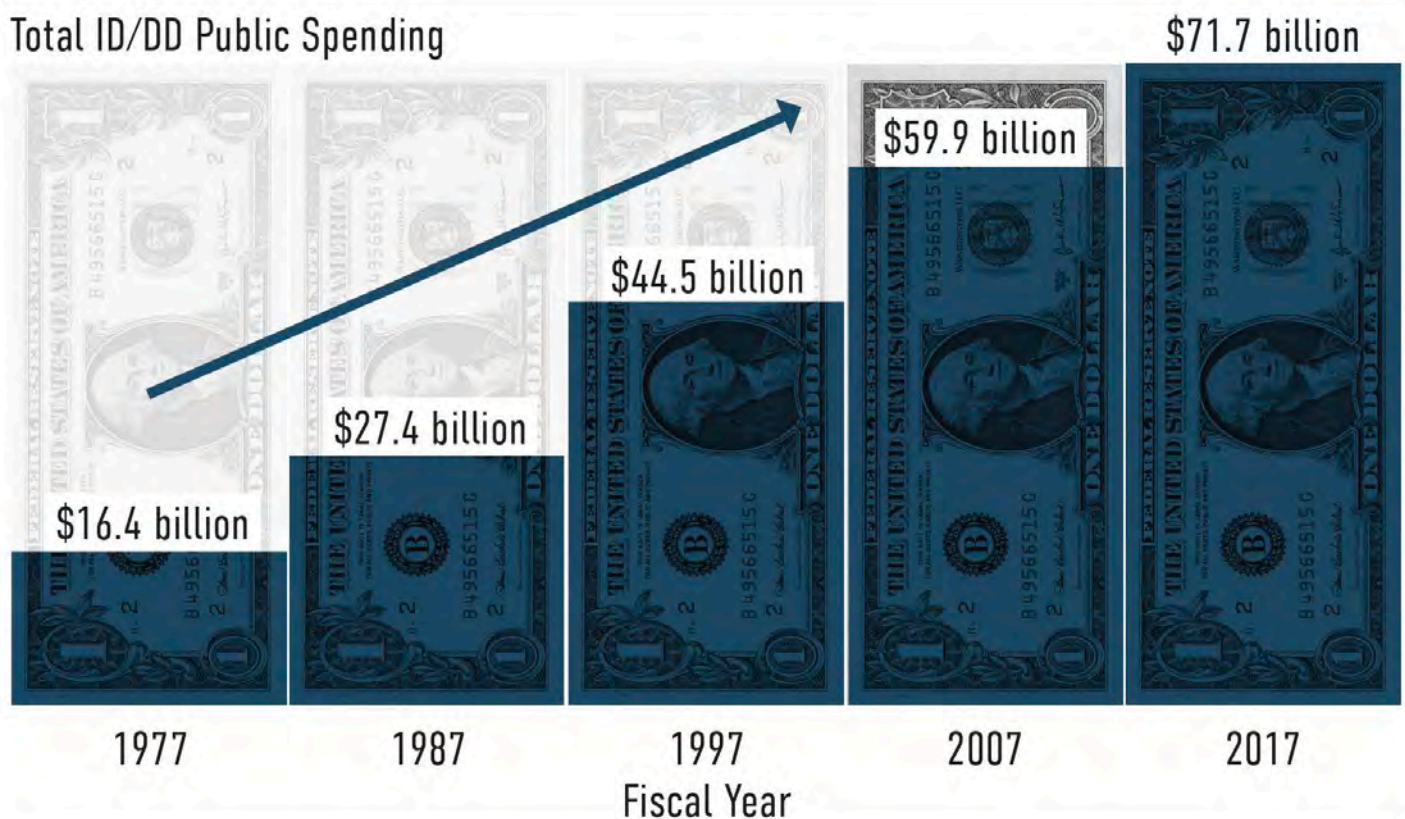
In 2017, most supports were funded by Medicaid.

Medicaid programs for people with ID/DD include the Home and Community-Based Services (HCBS) Waiver and Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID). Medicaid HCBS Waivers fund supports and services provided in community settings. HCBS services can include residential supports, employment supports, home modifications and other types of supports. ICF/IID services are provided in institutions.

77%
Medicaid spending

23%
other spending
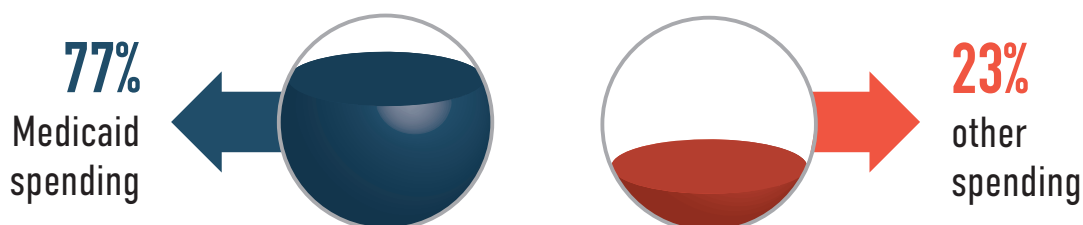
Spending has shifted from institutions to communities.

Spending on services provided to people living in institutions decreased from 12.3 billion in 1977 to $7.2 billion in 2017. But spending on services provided to people in community settings increased from $4.1 billion to $64.4 billion.

$64.4 billion

$12.3 billion

$4.1 billion

$7.2 billion

1977

1989

2017

In 1989 community spending surpassed institutional spending and continued to increase up to 2017.

In 1989, community spending exceeded spending on institutions.

Until 1989, the government spent more money on services in institutions. Since 1989, more money has been spent on services in community settings. In 2017, 90% of all spending on services for people with ID/DD was for services provided in community settings.

The amount of money states spend on supports and services varies.

To compare the amount of money that states spend on services and supports for people with ID/DD, researchers use a measurement called **fiscal effort**. This measurement lets us compare states with one another, even though they have different policies and state wealth.

Average **fiscal effort** for the United States in 2017 was $4.40. Some states spent as little as $1.62 per $1,000 of income while others spent as much as $11.65 per $1,000 of income.

Fiscal effort is the amount of money spent by the state and federal government on ID/DD supports and services per $1,000 of statewide personal income. In other words, how much a state spends on ID/DD services considering state wealth.

Total fiscal effort for 2017
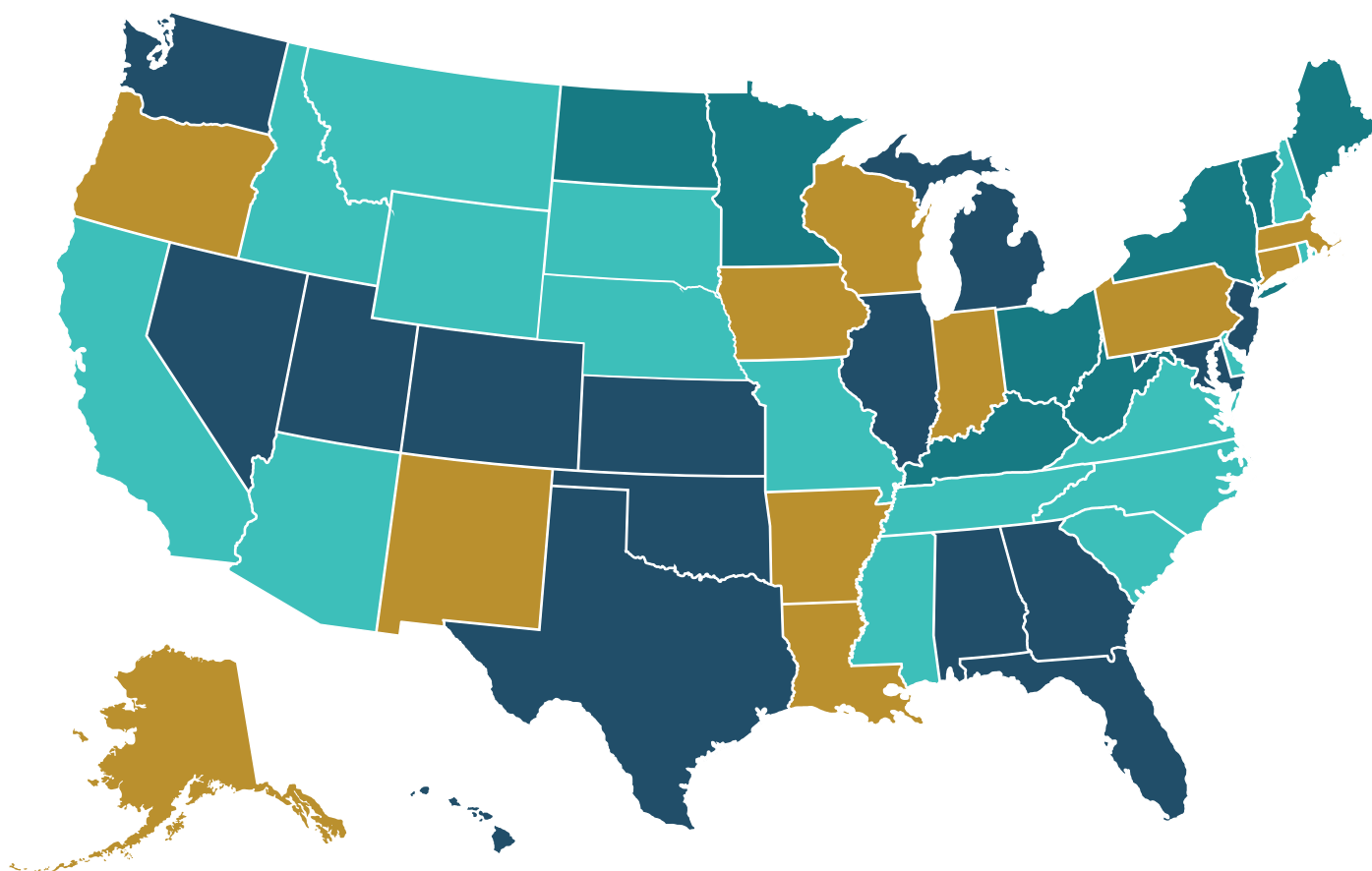
$1.62-$3.50 fiscal effort	$3.51-$5.00
$5.01-$6.50	$6.51-$11.65

Virginia's story shows how state policy affects spending.

After the 2012 investigation of Virginia's public state-run institutions for people with ID/DD by the U.S. Department of Justice, the Commonwealth of Virginia agreed to pay for Medicaid waiver services for 4,170 more people by June 30, 2021. They agreed to create an individual and family support program to serve 8,700 more people by June 30, 2022. To pay for these additional services, Virginia changed three existing waiver programs, closed four institutions, and helped many people move from institutions to community settings.

In 2011, the year before the agreement was settled, Virginia ranked 20th in the nation for institutional spending and 45th for community spending. By 2017, it decreased to 23rd for institutional spending and increased to 25th for community spending.
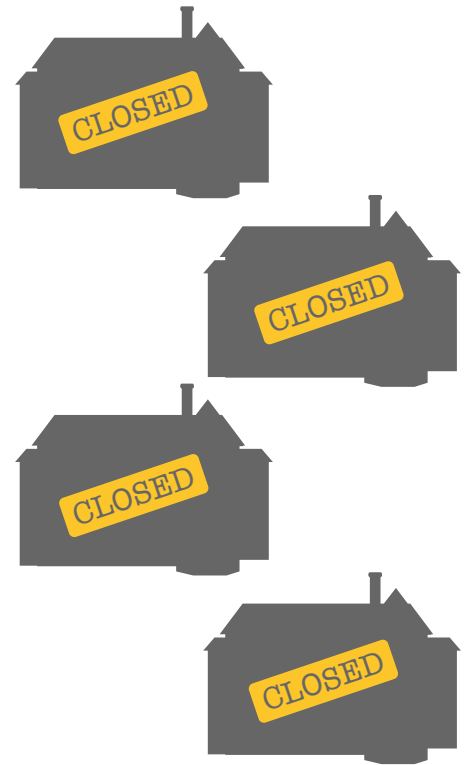
Fiscal effort for ID/DD services in Virginia

Year	Institutional fiscal effort	Community fiscal effort
2011	$0.65	$1.94
2012	$0.68	$2.40
2013	$0.69	$2.54
2014	$0.59	$2.61
2015	$0.46	$2.65
2016	$0.36	$4.06
2017	$0.37	$4.12

Legend: ■ Institutional fiscal effort ■ Community fiscal effort
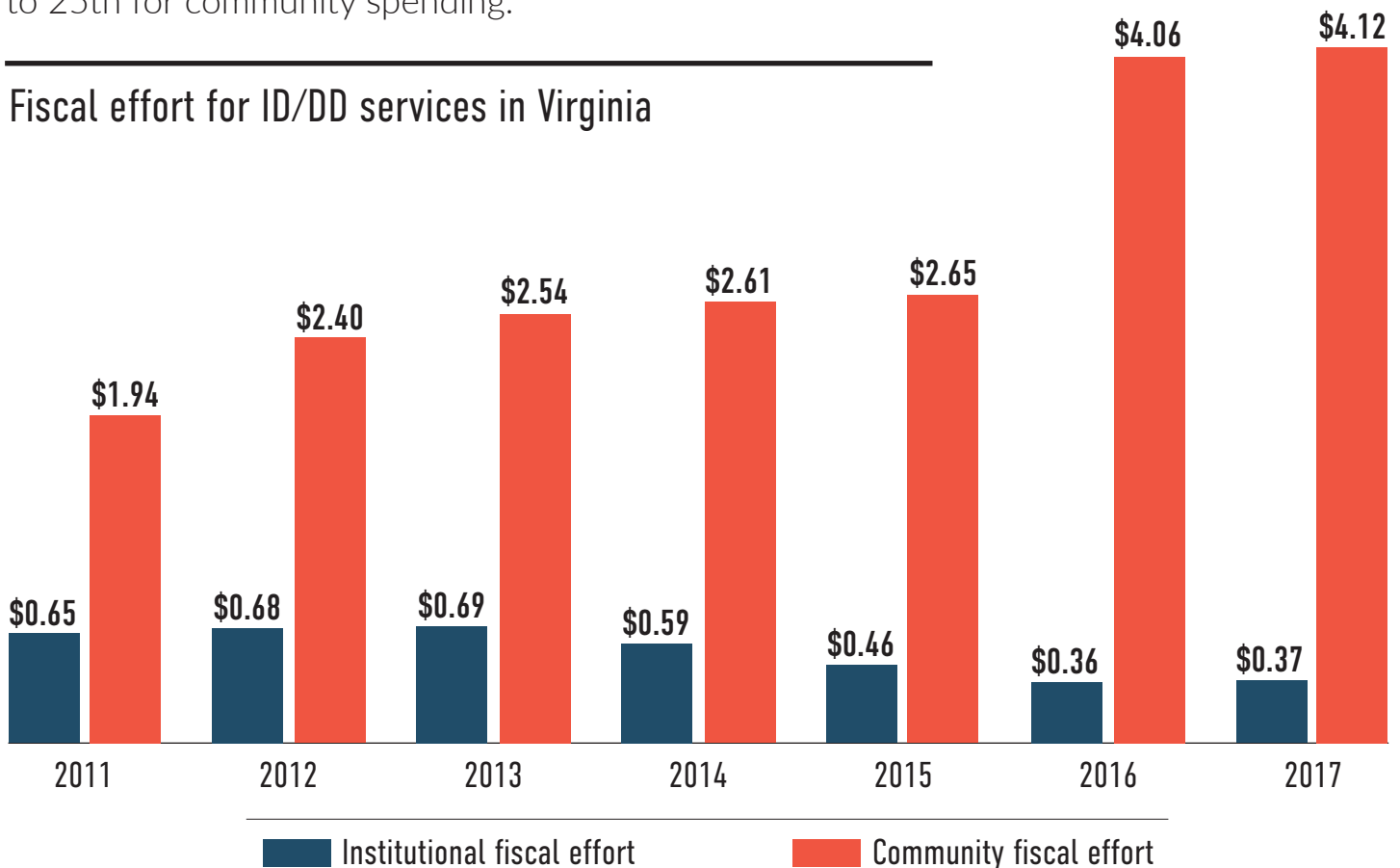
Technology

> **My friend has a cell phone. Why can't I have one? Technology, and the help of others, can help me become more independent.**
>
> - Heidi Myhre

Getting a better quality of life with technology.

Before he had technology to make his life better, Mike was bored. He wondered what was the point? He waited for staff to help him contact his family, turn his lights on or off, turn on his TV or change the channel. He wished he could have a social life, a regular life like everyone else. He wanted more. There had to be more.

When he found technology he could use, Mike was ready. In his home Mike now controls the controls! He turns on lights and changes channels on the TV. He sends texts and calls family and friends on his own. He spends his days testing new technology and sharing his experiences with his peers and technology companies. In Mike's own words, "It changed my life completely because before I felt like I had no purpose in life and I was bored and sad. Now I can do things I could never do before."

Technology supports wellbeing and community engagement.

Technology helps people with ID/DD participate in their communities as they want.

People use their smartphones to connect with friends and family. They use smart home devices to tell them someone is at the door or to connect with coworkers or teachers to learn new skills. This should be no different for people with ID/DD.

Programs and services should provide access to technology to support community living.

"I ask my tablet what the weather is so I can get ready for the day. I ask it what I am doing for the day. It answers my questions when I have things that I want to learn about.

I talk to my mom and dad with it. I can listen to any music I like! It reminds me of things I need to do too. It helps me to be independent."

- Kara Brouhard

More money is needed to fund technology for people with ID/DD.

From 2007 through 2017, public spending on smart homes, personal support technology, and remote supports for people with ID/DD increased. However, spending on technology ($16.6 million in 2017) is far less than 1% of overall spending on ID/DD supports and services which was $71.7 billion.

The amount of money spent on technology has increased very little in the last 10 years. Most of the spending ($12.2 million in 2017) pays for personal support technology such as hearing aids or wheelchairs. Less is spent on remote supports ($3.6 million). Only a tiny amount was spent on smart home technology ($827,000).

Spending for technology solutions in millions by year

Year	smart homes	personal support technology	remote supports
2008	$77,709		
2009	$90,096		
2010	$186,964	$2,595,690	
2011	$189,720	$3,532,635	
2012	$142,183	$6,129,922	$94,123
2013	$158,131	$4,690,650	$590,512
2014	$204,310	$4,298,494	$1,289,074
2015	$379,638	$4,295,695	$2,027,417
2016	$698,681	$9,765,152	$3,189,219
2017	$827,285	$12,175,455	$3,645,571

■ smart homes   ■ personal support technology   ■ remote supports
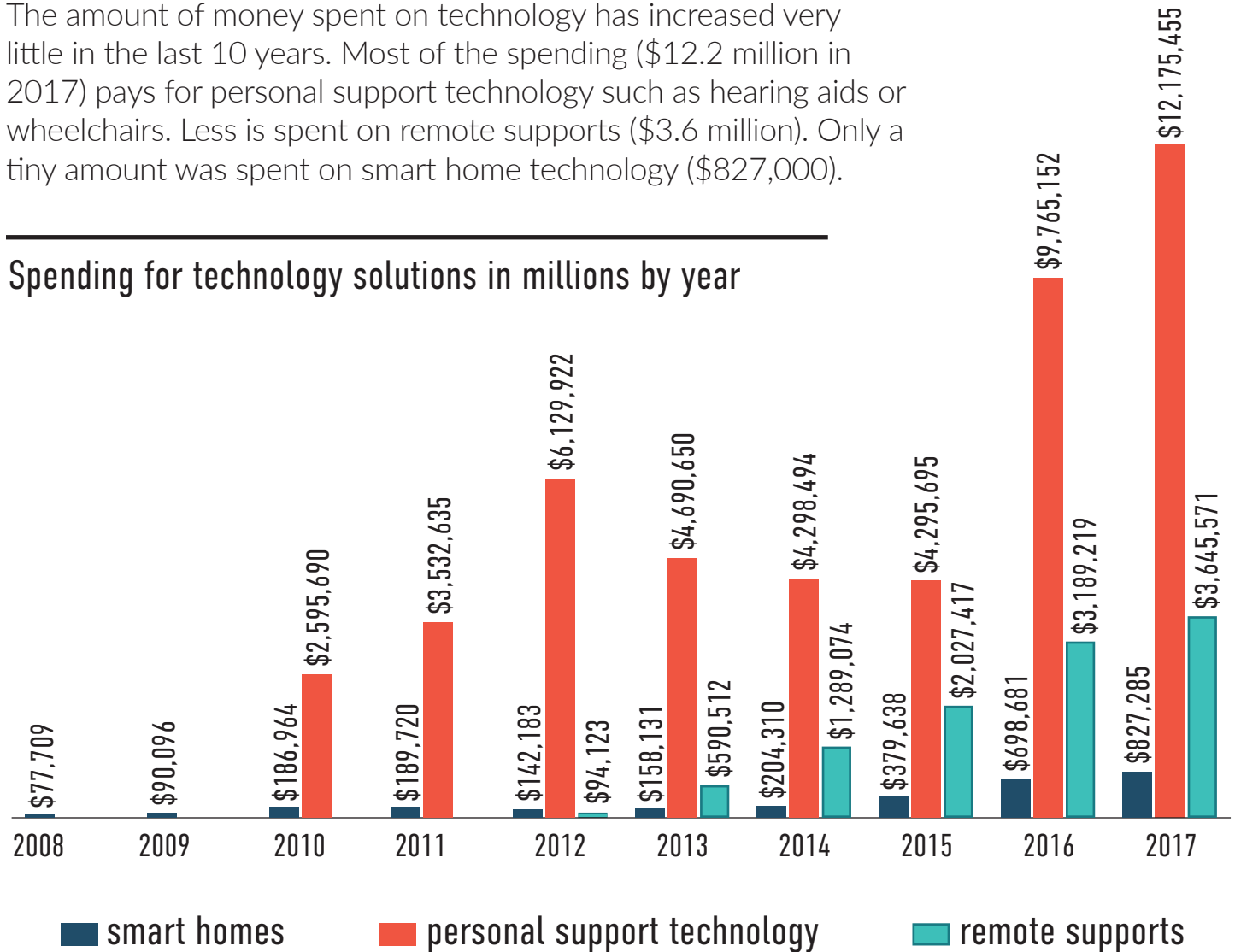
States fund technology several different ways.

States use an average of 12 different funding authorities to buy technology services, applications or solutions for people with ID/DD. Most states use Medicaid Home and Community-Based Services Waiver funds. They also use Medicaid State Plan and Vocational Rehabilitation funds.

Few states require technology to be considered when people are planning the services they will use.

Technology First policies require individual service planning teams to consider technology options when person-centered plans are developed. Technology offers clear solutions to very challenging issues such as direct support worker shortages, healthcare access, unemployment, and service delivery limits.

In 2020, 17 states and the District of Columbia had **Technology First** initiatives. Those states are Alaska, Colorado, Connecticut, Hawaii, Indiana, Maryland, Minnesota, Missouri, New York, Ohio, Oklahoma, Pennsylvania, South Carolina, South Dakota, Tennessee, Washington, and Wisconsin.

"Technology First gives me and my friends technology like everyone else."

- Julian Wang

States are buying new kinds of technology.

Technology solutions is an umbrella term that includes not only assistive technology, but also technologies with advanced accessibility features. In 2019, state ID/DD agencies listed the top technology solutions they wanted to invest in. Those include remote supports, smart homes, broadband, telehealth, and transportation technologies.

Top technology solutions for states in 2019

remote supports

smart homes

broadband

telehealth

transportation technology
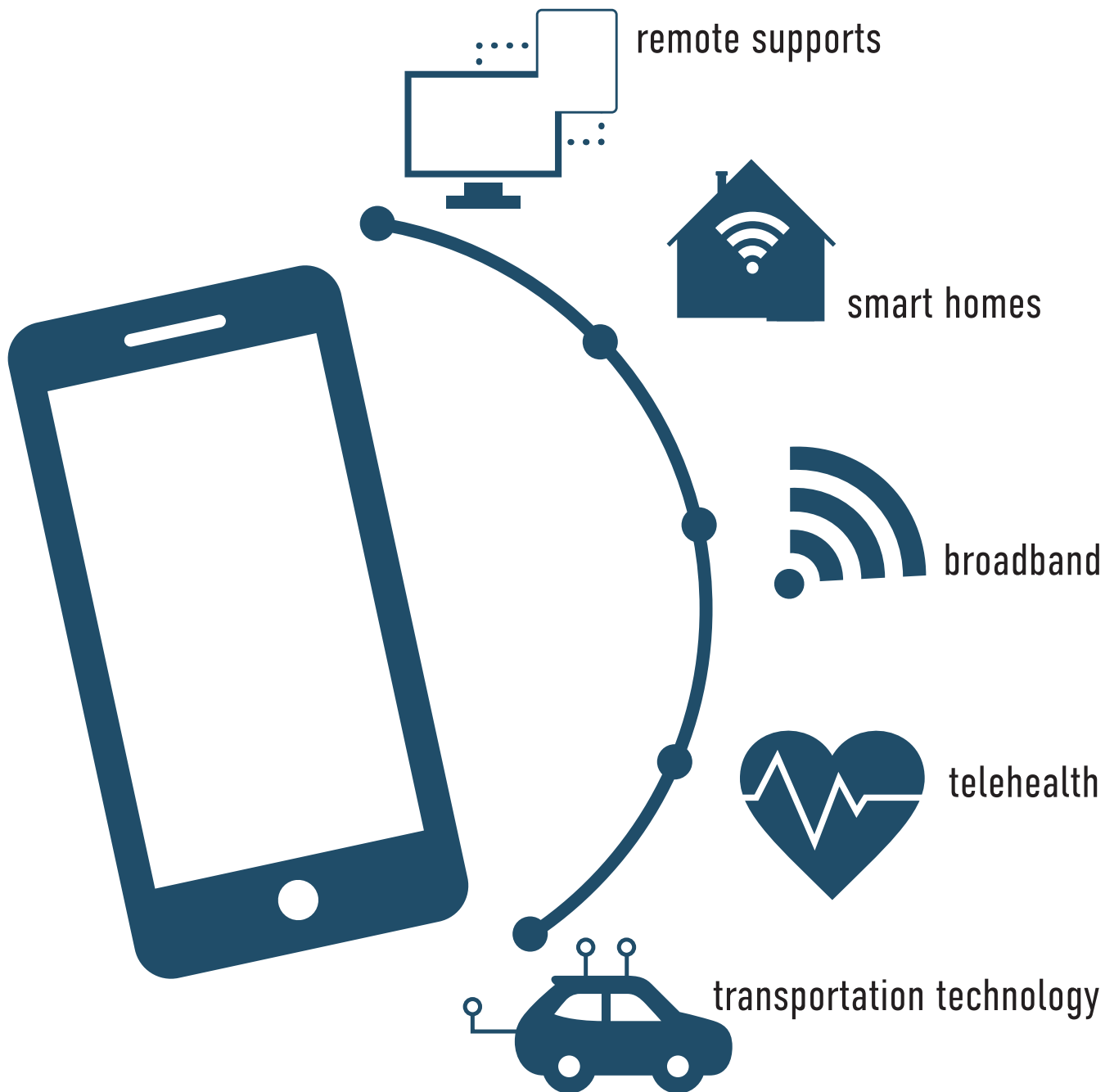
Conclusion

People with ID/DD want:

- Homes of their own, not institutions;
- Jobs and meaningful ways to spend their days;
- Access to funded supports; and
- Access to easy to use technology.

A note from our advisors

A team of people with intellectual and/or developmental disabilities helped develop this report. They helped to break down difficult language and make complex ideas more understandable. They provided insights and suggestions for improvement. They were very clear that we need to do more to make our communities truly inclusive and welcoming for people with ID/DD. Thirty years of progress is just the beginning.

Following are brief summaries of conversations with project advisors. They describe the reality of services and supports today and the challenges we must face going forward.

Community living

We want homes of our own, not institutions. We've made progress in getting away from the big state-run institutions, but it's not just the big institutions that are segregating people from their communities. It's also nursing homes and psychiatric facilities and group homes that have lots of people in them. A group home of seven or more people is still an institution. Some group homes are great but others are doing poorly.

> "We have evolved in terms of our view of disability … it's not 'hush hush' like the old days."
>
> – Nicole LeBlanc

Getting a home of your own is a big process with many steps, like finding a place to live, getting supports arranged, and figuring out how to stay safe. Not every story has a good outcome. Sometimes it doesn't work out. Some people go through three or four providers before finding the right place. It's not a perfect system.

> **"There were many years I had to fight just to be in the community . . . and not end up back in an institution."**
>
> **– Heidi Myhre**

Today, young people do not know what residential institutions are. To them, institutions may mean sheltered workshops. There are places like farmsteads and gated communities, segregated facilities that look nice but are really just new institutions. We have a lot of work to do to make sure we are welcome in our communities.

Employment

We want real jobs and meaningful ways to spend our days. We are human beings and we deserve what people without disabilities have. For those of us who work, we should receive fair pay, not less than people without disabilities. We want job training, some of us need job supports, and that's okay. Everybody needs help sometimes, whether or not they have a disability. We want to have the opportunity to move up a career ladder. More should be done to make this a reality on the federal level.

> **"We should not be looked down on or given less than people without disabilities."**
>
> **– Max Barrows**

Not everyone has or wants a job. Some people choose to do unpaid volunteer work. Some spend their time doing other activities. But our days should be spent doing meaningful things and we should be able to choose what they are.

Expenditures

Money needs to support people with ID/DD living in our communities not institutions. Money should support us to live the lives we want.

> They [the policy makers] don't know what it means to live like we do in regards to how we spend our money.
>
> – Ashley Wolfe

Each state spends different amounts of money to support people with ID/DD. Our legislators need to know we matter and that we need more money to pay for community supports.

Technology

Technology can make our lives easier. Our smartphones have alerts that remind us to do things like go to an appointment or take medications. We can connect with others through email and social media. Our phones and computers can speak to us and help connect us with the world. Some of us need really complex technology such as medical devices. Others need common technologies like wheelchairs or hearing aids to participate in our communities.

> "Technology is important for people who communicate differently. Legislators need to understand how important it is for us to have access to current technology. We should all have broadband internet access so we can connect with doctors, family members, and friends. We need technology that is easy to use."
>
> – Julian Wang

A Note from the Administration for Community Living

The vision of the Administration for Community Living (ACL) is that all people with disabilities can live independently and participate fully in their communities. ACL believes that every person has the right to make choices and to control the decisions in and about their lives. This right is defined by the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and other policies. It includes the right to make to make decisions about where, how, and with whom people with intellectual and developmental disabilities live and work, as well as the other choices that people make every day to ensure a good quality of life.

For over thirty years, the Administration on Disabilities at ACL has funded three longitudinal studies to track the nation's progress in fulfilling this vision. Those studies document the history, current status, and future of services and supports for people with intellectual and developmental disabilities in the United States. *30 Years of Community Living* summarizes three decades of research to support individuals with lived experiences, families, service providers, policymakers, and advocates to drive improvements in their communities. Collecting and analyzing trends in data helps us to understand the communities we serve and measure the impact and effectiveness of our initiatives and interventions over time. We hope you use this information to make informed decisions for yourself, your loved ones, and others for whom you advocate.

Acknowledgements

Project Reports and Websites

More information about the state and national trends is available. See these project reports and websites or contact the report authors for this information.

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Funding Acknowledgements

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Recommended Citation

Larson, S.A., Butterworth, J., Winsor, J., Tanis, S., Lulinski, A., and Smith, J. (2021). *30 years of Community Living for individuals with intellectual and/or developmental disabilities (1987- 2017)*. Washington, DC: Administration for Community Living, U.S. Department of Health and Human Services.