Community Living for Individuals with Disabilities: A Look Back and Into the Future

Jennifer Johnson, Dana Fink and Katherine Cargill-Willis – Administration on Community Living

Sheryl Larson, University of Minnesota

Shea Tanis, University of Kansas

John Butterworth, University of Massachusetts

Longitudinal Data Projects of National Significance

STATE OF THE STATES
IN INTELLECTUAL AND
DEVELOPMENTAL DISABILITIES

RISP

UNIVERSITY OF MINNESOTA
Driven to Discover℠

ICI **ThinkWork!**
StateData.info
INSTITUTE FOR COMMUNITY INCLUSION, UMASS BOSTON

30 Years of Community Living
www.acl.gov/30years

Communities are better when everyone is included

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

For adults, community living is about choosing

- Where and with whom we live
- Our friends
- What we do in our free time
- How we earn and spend money
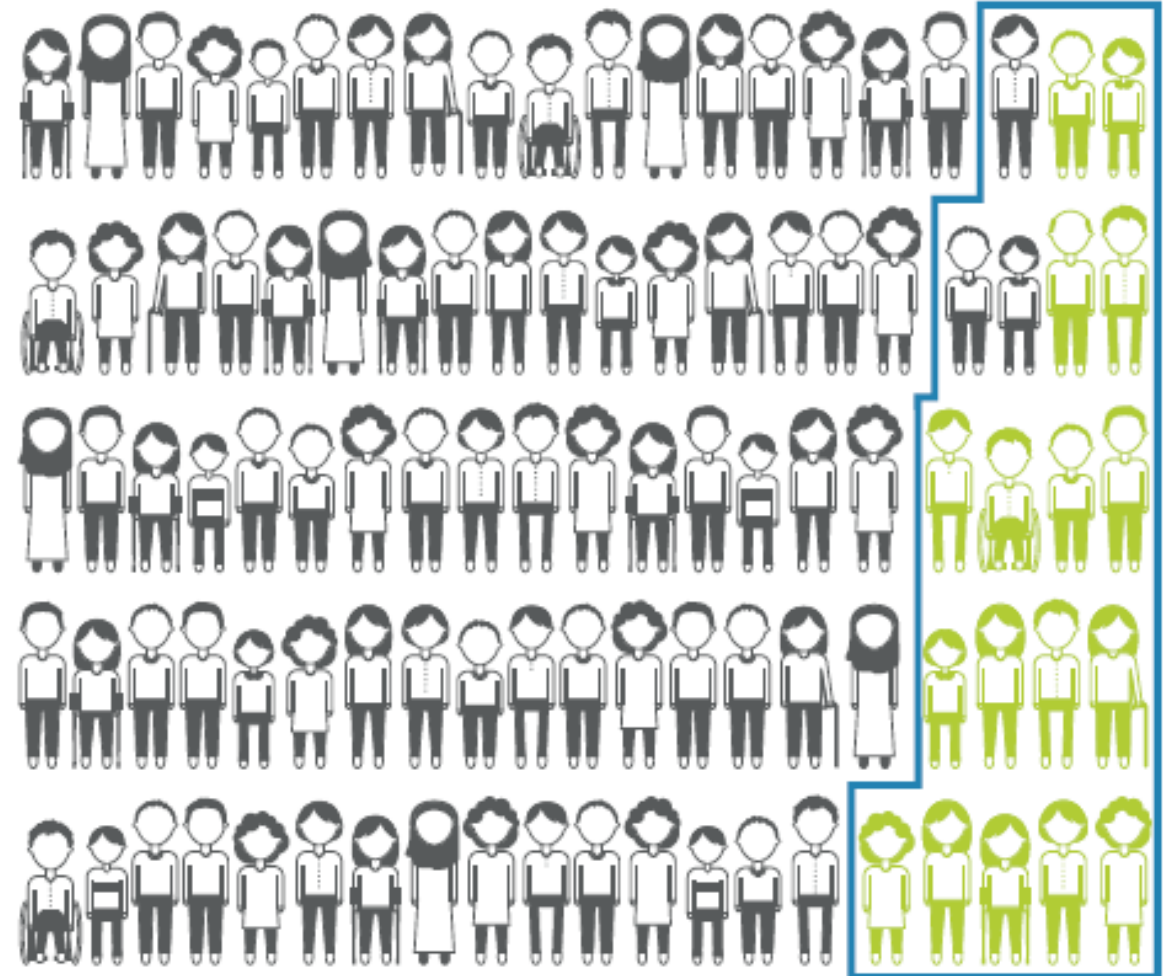
People with ID/DD want:

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

This story is about...

- 7.4 million people in the US have intellectual or developmental disabilities

- 1.48 million are served by state IDD agencies including 2 in 5 adults with IDD

- About 910,000 (62%) are 22 years or older

7.38 million people in the United States had Intellectual or Developmental Disabilities (IDD) in 2017
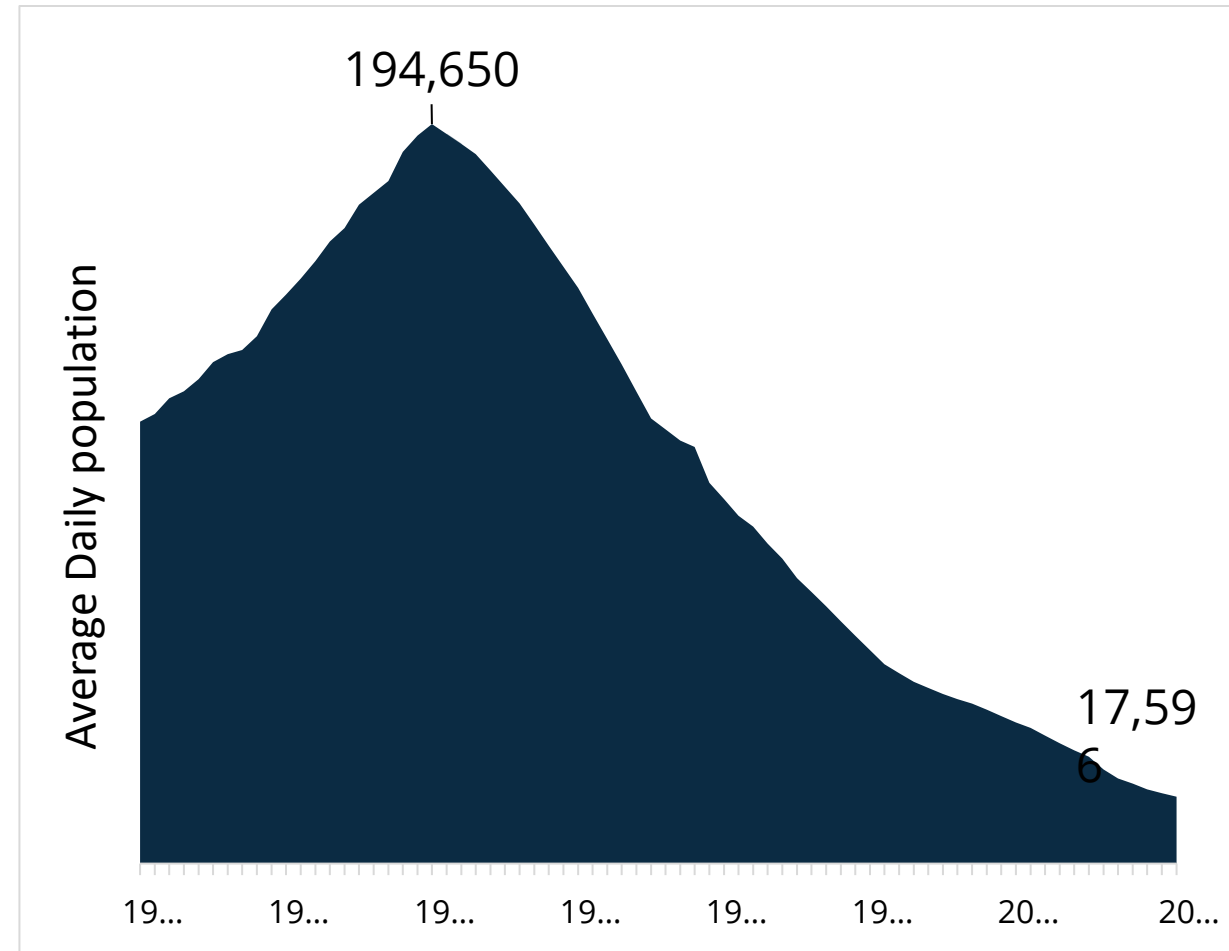
20% 1.48 million people with IDD were known to or served by state IDD agencies

17% 1.28 million people with IDD received long-term supports or services through state IDD agencies
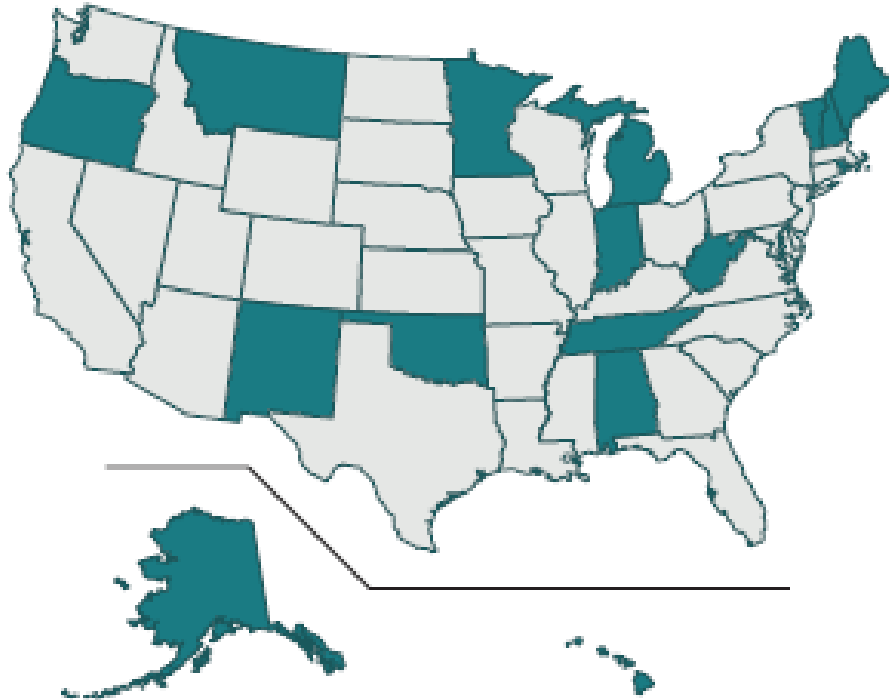
State ID/DD Institutions used to be the only publicly funded support option

- For almost 100 years people with ID/DD had to move to institutions to get an education or training.

- Many people entered institutions as young children and never left.

- In 1967, 194,650 people with IDD lived in state institutions. Half were children.

- By 2018, only 17,596 people remained

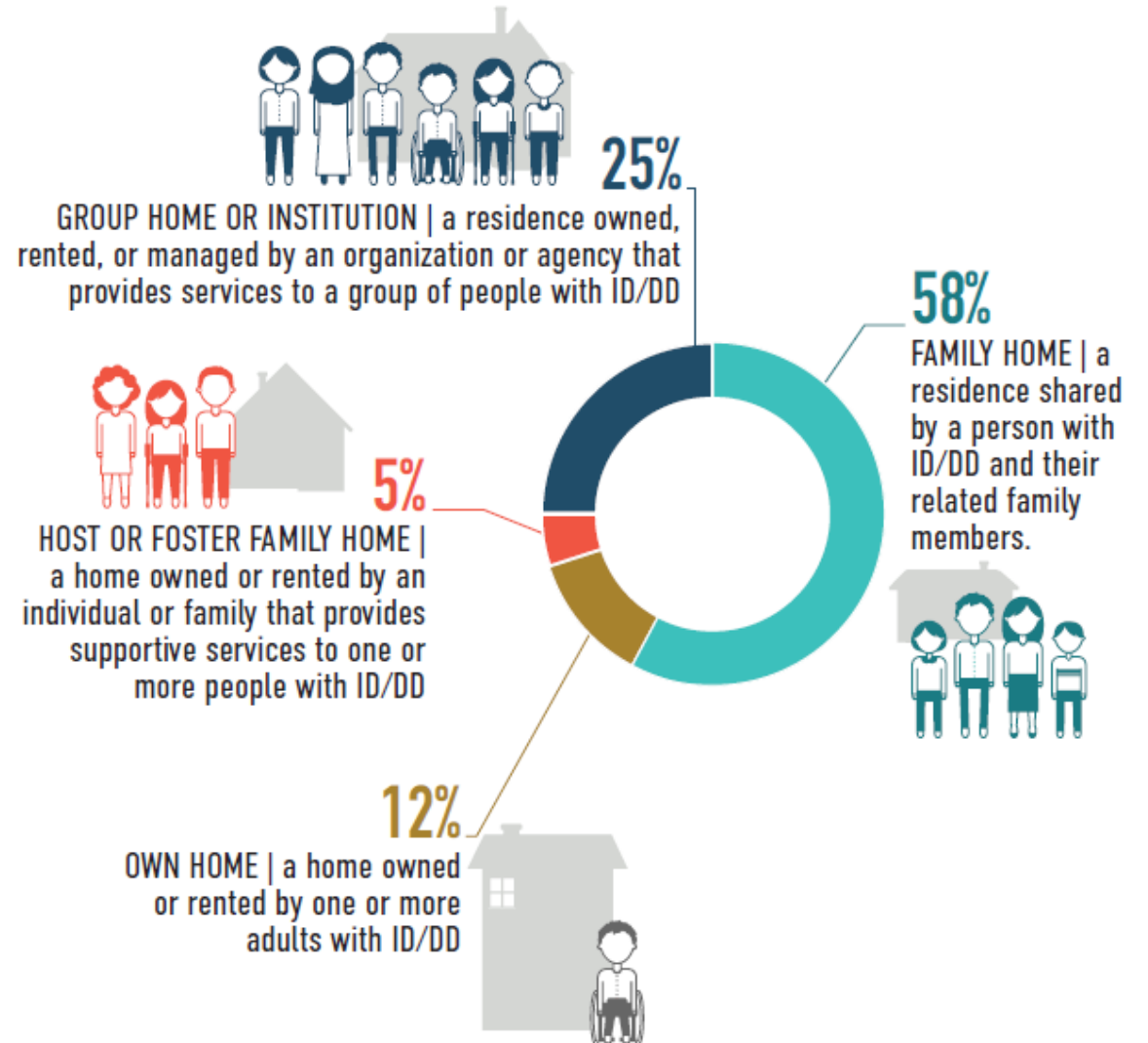# 17 states closed all their state IDD institutions

no open facilities

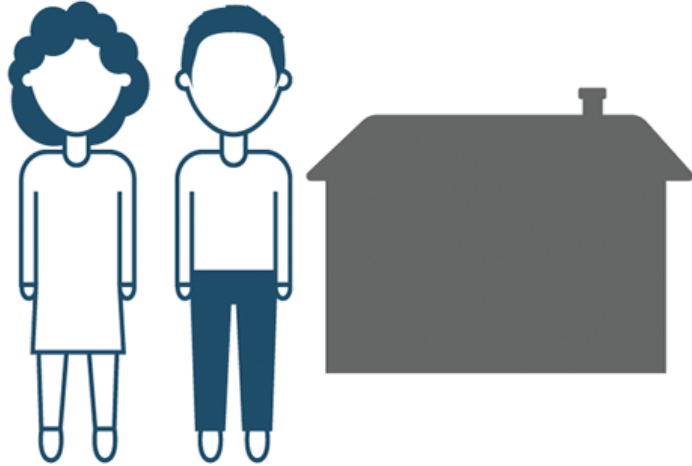# 4 of 5 people who lived in institutions now live in community homes

institutional settings

community homes

Today, amongst people with ID/DD getting supports…

- 58% live with a family member
- 12% live in a home of their own, alone or with a roommate
- 5% live with a host or foster family
- 25% live in a group home or in an institution.

25%
GROUP HOME OR INSTITUTION | a residence owned, rented, or managed by an organization or agency that provides services to a group of people with ID/DD

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
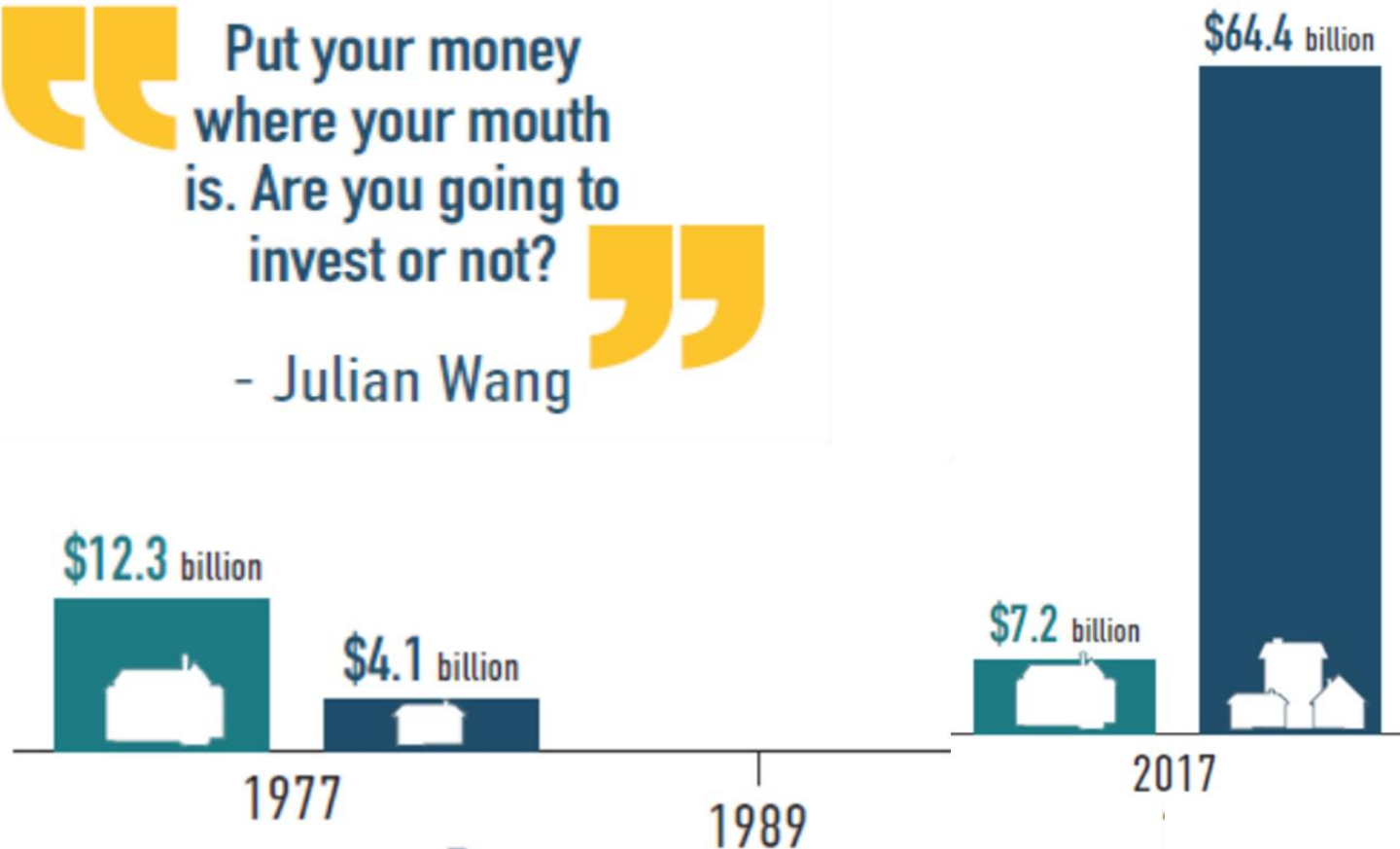
A lot has changed in the last 30 years

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

30 Years of Community Living | acl.gov/30years

Spending shifted from institutions to community supports

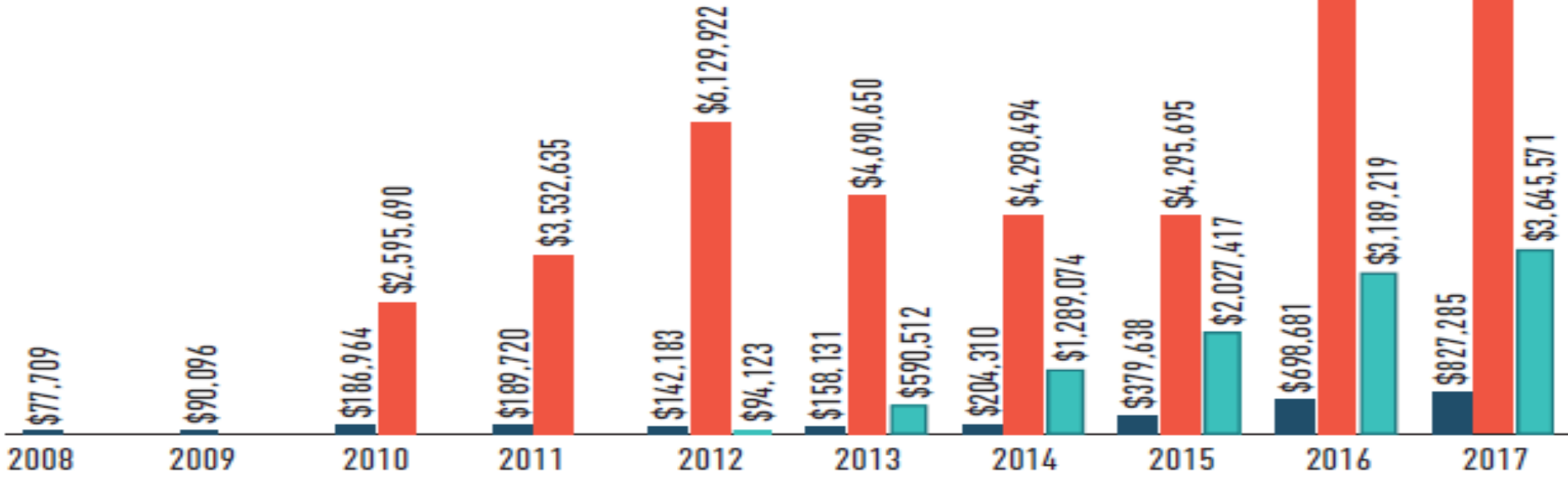"Put your money where your mouth is. Are you going to invest or not?

- Julian Wang

$12.3 billion

$4.1 billion

$7.2 billion

$64.4 billion

1977

1989

2017

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

How much a state spends on ID/DD services and supports varies

Total fiscal effort for 2017

Fiscal Effort
How much a state spends on ID/DD services considering state wealth

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

Technology solutions account for less than 1% of total expenditures
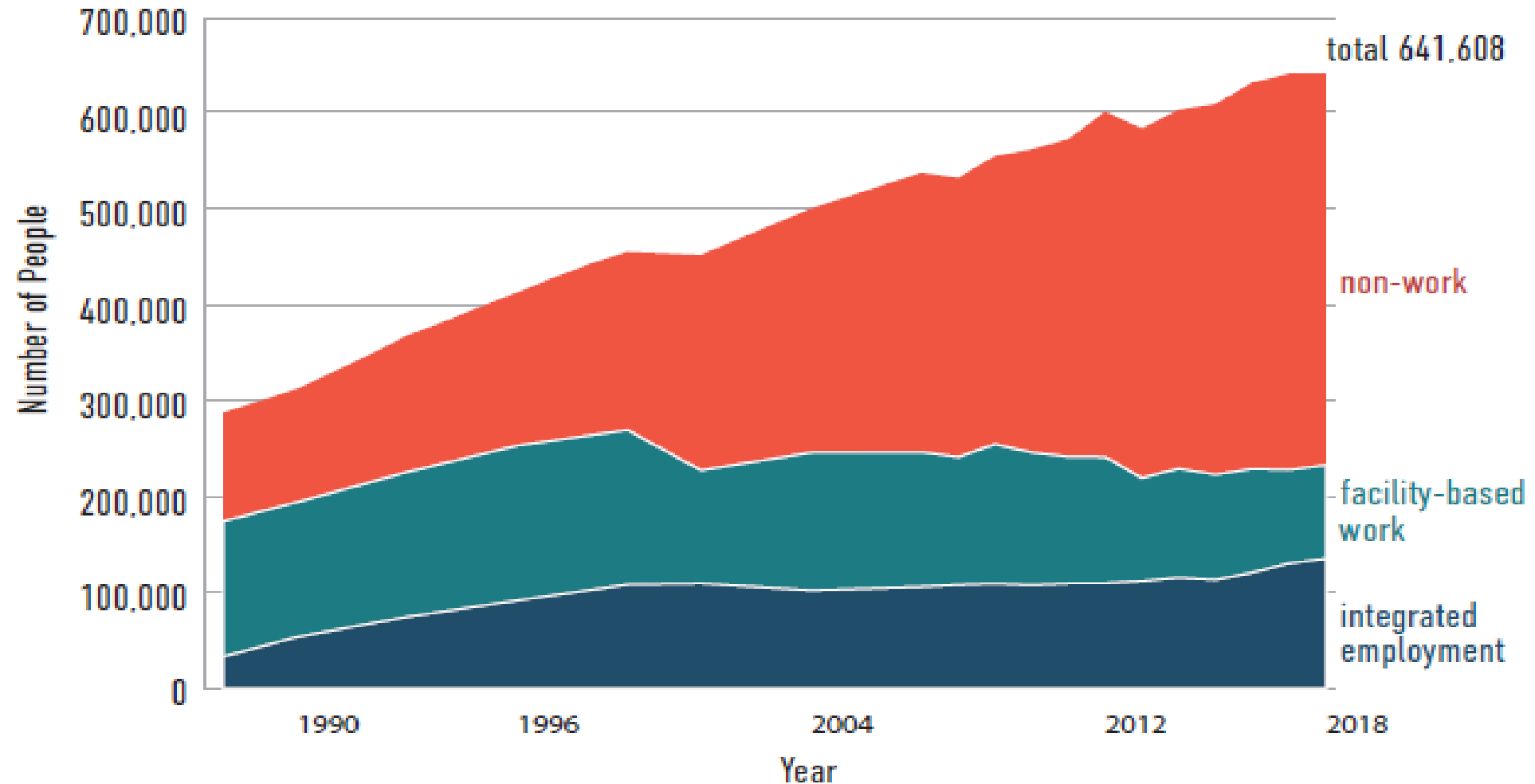
Spending for technology solutions in millions by year

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

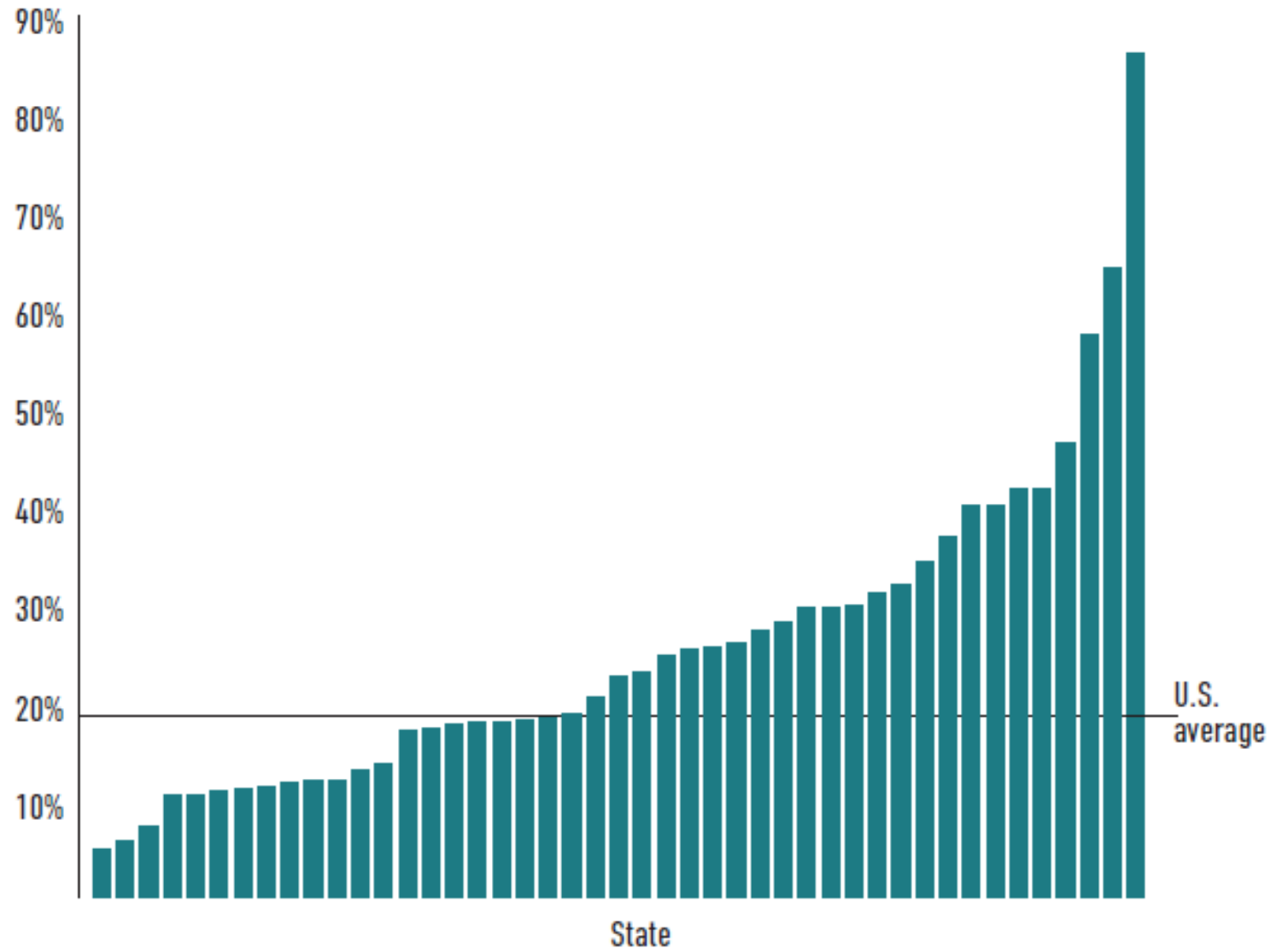■ smart homes   ■ personal support technology   ■ remote supports

Participation in integrated employment services is increasing but most people do not have community jobs

Access Varies by State

Percent of people with ID/DD who get day or employment support who ==receive services to help them find or work in== competitive integrated jobs

I am not fully part of my community when:

- My job pays less than minimum wage.
- Most coworkers have a disability.
- My employer is also paid to provide supports.
- Activities are chosen because the group is going.
- Everyone doing the activity gets supports.
- I go places without knowing why.

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

- Max Barrows

We are not finished, yet

- 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.
- Many people are waiting for supports, including some who have funds allocated.
- Opportunities differ by state.
- Not every story has a good outcome. Some people go through 3 or 4 providers before finding the right place.
- Acute staffing shortages are compromising access to needed supports.
- Access to technology is severely limited for people with ID/DD.

"Some group homes are great but others are doing poorly."

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

– Heidi Myhre

We need better access to technology.

"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

"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

Change how we support people with ID/DD

"We should be… developing a robust long-term care system that plans for disability. It's something we're all going to face sooner or later…. But **it shouldn't have to happen to you to matter to you.**"

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

– Nicole LeBlanc

Acknowledgements