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

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Longitudinal Data Projects of National Significance

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
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

4 of 5 people who lived in institutions now live in 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.
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

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.

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

Total fiscal effort for 2017

- $1.62-$3.50
- $3.51-$5.00
- $5.01-$6.50
- $6.51-$11.65 fiscal effort
Technology solutions account for less than 1% of total expenditures.
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
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