NH RAPP Housing Presentation
June 1, 2022

Resources from the University of Minnesota, Institute on Community Integration, Residential Information Systems Project

Overview

- This webinar will focus on key housing issues impacting people with disabilities with authors from the latest issue of The Disability RAPP.

- During this webinar, our moderated panel will explore important housing topics like universal design, institutional qualities, and where people with IDD currently live.

- The Disability RAPP is a collaborative effort by the Disability Rights Center-NH, UNH Institute on Disability, and New Hampshire Council on Developmental Disabilities. The latest issue focuses on Disability and Housing and is available at drcnh.org

What can we learn from states who have moved away from large institutions?

- It is possible to serve all people with IDD in individualized settings. People with all types and levels of disability have successfully moved from institutions to community settings.

- Early adopters of deinstitutionalization created lots of smaller institutions. They are now working to move from group homes to individualized settings.

- Late adopters can skip the small institution step and help people move to or to remain in individualized community homes.

- States continue to struggle to serve people with mild or moderate IDD whose behaviors are dangerous to others or who have been in the criminal justice system.

Where do former residents of state institutions go?

- Many policy shifts supported institution downsizing and closure
  - The law changed to require that all children including those with disabilities be able to attend school. This helped families and reduced the demand for institutions.
  - Medicaid offered funding but required states to reduce overcrowding in institutions
  - The Medicaid Home and Community Based Waiver offered supports to assist people to continue to live with family members
- Initially, people who left state-run IDD institutions moved to private institutions or large group homes.
- Now most people leaving institutions move to
  - small group settings (with four or fewer people) or
  - individualized settings (own home, family home, or host or foster family homes)

Have some states transitioned to community-based options better than others?

- There are tremendous state differences in how in-home and residential supports are organized.
  - Some states provided long-term support and services to 10x more people per 1,000 people than other states
  - Some states serve almost everyone in the home of a family members, others do not provide funding to support many people in family homes

Why is it important to collect, track, and analyze the place where people with IDD live? What can we learn from this information?

- National and state data have been key to helping legislators and policy staff monitor the services they provide and compare how they are doing with those in other states.

- Data are critical to identify successes and to find and fix problems.

- Key challenges
  - Separating the number of people with IDD who live in their own homes versus those living with a family member.
  - Having accurate and up to date information about unmet needs (waiting lists)
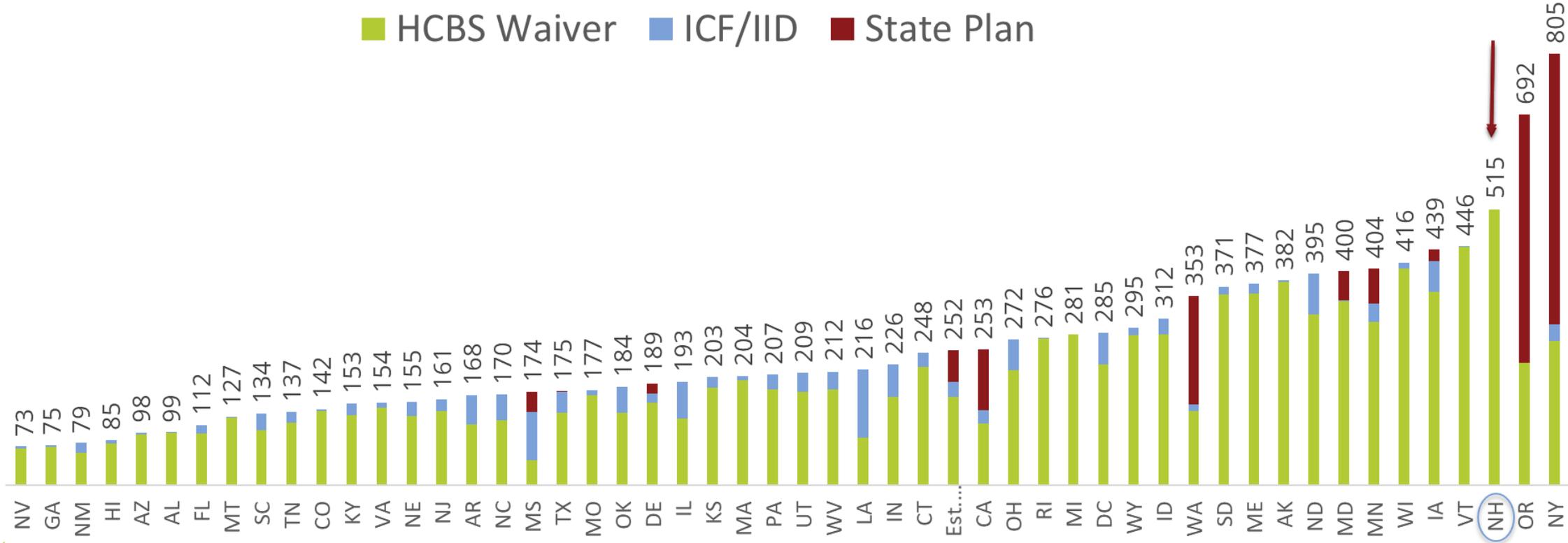
New Hampshire Facts 2021

- NH ranks in the top five states in terms of the number of people with IDD per 1,000 of the population who were getting Medicaid-funded LTSS (2018 data)
- The state reported no one living with a family member who had requested Medicaid Waiver funded supports was waiting for those supports.
- Where people with IDD getting long-term supports and services live
  - 97% of people in NH served by the state lived in homes with six or fewer people;
  - 95% lived in homes shared by three or fewer people.
  - 37% of people getting LTSS lived with a family member.
  - In 2019 there were approximately 93 people with IDD in nursing homes.
  - There was one non-state IDD facility serving 26 people.
  - There were 8 non-state IDD facilities serving 7 to 15 people.

NH served more adults with IDD per 100,000 of the population than all but two states (2018 ranking)

Legend: HCBS Waiver, ICF/IID, State Plan

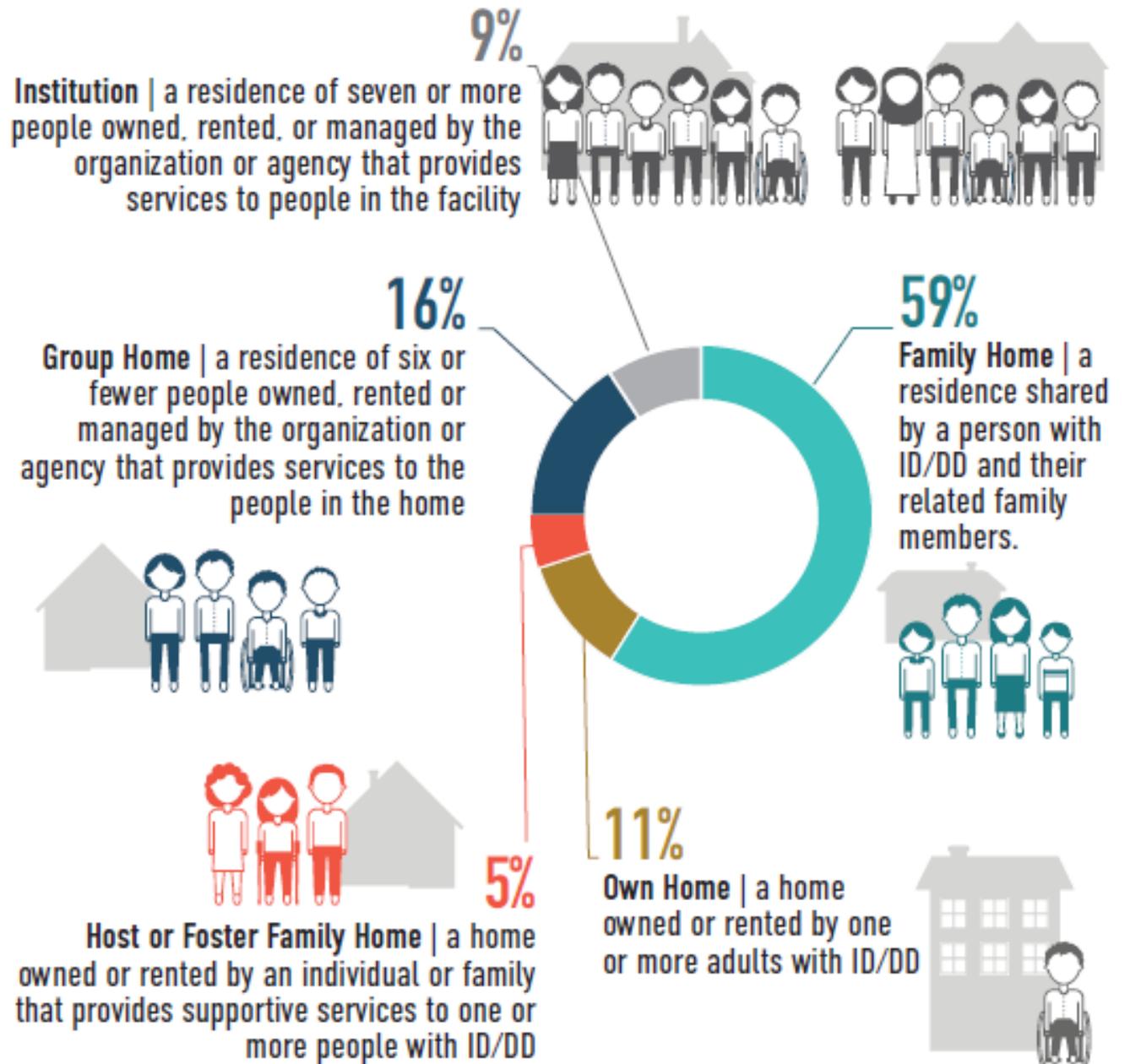| State	Value
NV	73
GA	75
NM	79
HI	85
AZ	98
AL	99
FL	112
MT	127
SC	134
TN	137
CO	142
KY	153
VA	154
NE	155
NJ	161
AR	168
NC	170
MS	174
TX	175
MO	177
OK	184
DE	189
IL	193
KS	203
MA	204
PA	207
UT	209
WV	212
LA	216
IN	226
CT	248
Est...	252
CA	253
OH	272
RI	276
MI	281
DC	285
WY	295
ID	312
WA	353
SD	371
ME	377
AK	382
ND	395
MD	400
MN	404
WI	416
IA	439
VT	446
NH	515
OR	692
NY	805

Deinstitutionalization Facts

- There are only 1/10th as many people in state run institutions now as there were in 1967.

- If the trend continues we could see the last state run institution close between 2025 and 2030 and the last non-state institution by 2040.

- There are now more people in large non-state facilities than in large state run facilities

- Most people living in state IDD facilities live in Texas, Illinois, New Jersey or North Carolina.
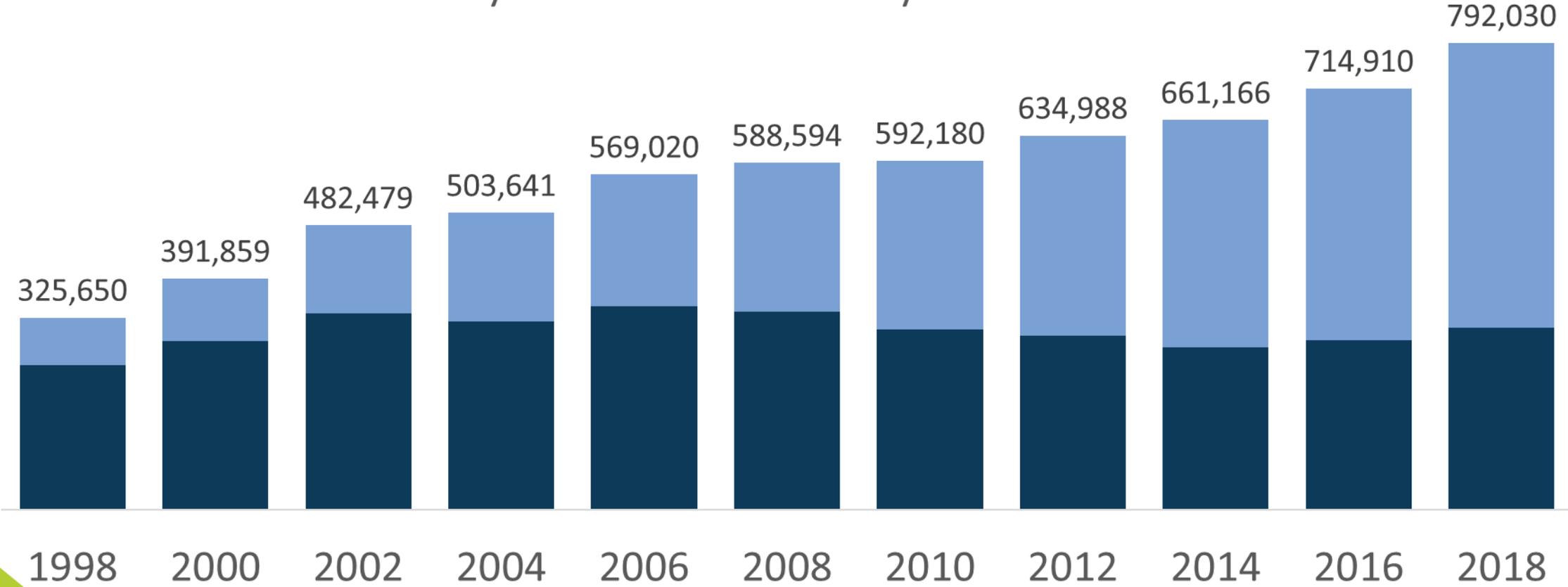
Most LTSS recipients live with a family member

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

59%

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

11%

Own Home | a home owned or rented by one or more adults with ID/DD
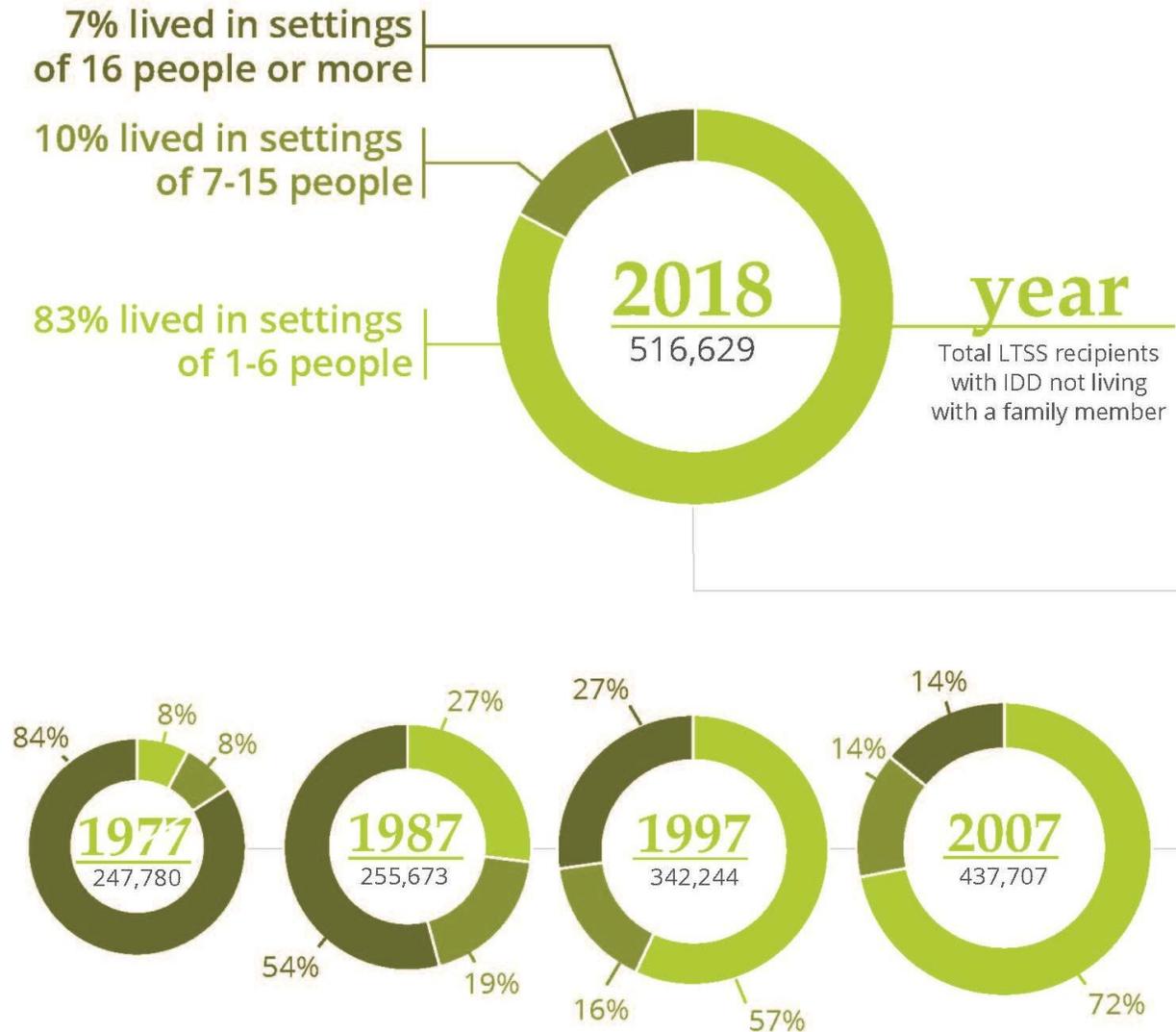
Nearly all the change in where people with IDD live is due to increased Waiver funded supports for people living with family members.

■ Family No Waiver ■ Family with Waiver

325,650 — 391,859 — 482,479 — 503,641 — 569,020 — 588,594 — 592,180 — 634,988 — 661,166 — 714,910 — 792,030

1998 2000 2002 2004 2006 2008 2010 2012 2014 2016 2018

Almost all people not living with a family member share a home with 6 or fewer service recipients

7% lived in settings of 16 people or more

10% lived in settings of 7-15 people

83% lived in settings of 1-6 people

2018
516,629

year
Total LTSS recipients with IDD not living with a family member

1977
247,780
84%
8%
8%

1987
255,673
27%
54%
19%

1997
342,244
27%
16%
57%

2007
437,707
14%
14%
72%

State IDD agencies serve 46% of adults with IDD in the US

Estimates	Children	Adults	Total
N People with IDD	5.3	2.1	7.43
N Served by State IDD agencies	0.57	0.97	1.55
% of population served	11%	46%	21%

People served in millions

7.43 million people in the United States had Intellectual or Developmental Disabilities (IDD) in 2018
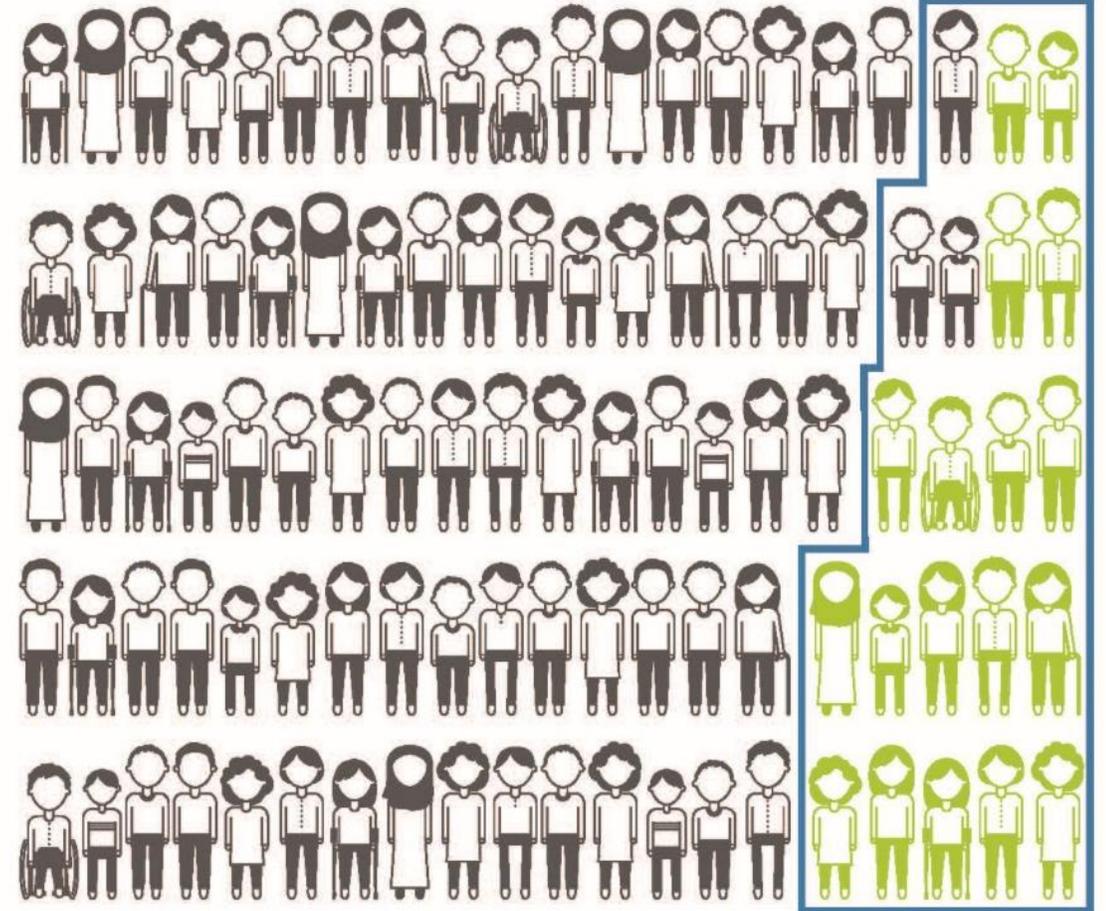
21% 1.55 million people with IDD were known to or served by state IDD agencies

18% 1.31 million people with IDD received long-term supports or services through state IDD agencies

Note: U.S. IDD prevalence estimates from 1994/5 and 2017 National Health Interview Surveys

Policy Recommendations

- Workforce shortages made more severe by the COVID-19 pandemic threaten access to home and community-based supports for people with IDD. Policy makers must address those shortages to ensure that people with IDD can move to or remain in their own homes and other community settings while getting needed supports.

- As the remaining large state-run IDD facilities close, the focus of deinstitutionalization efforts will shift to facilities operated by non-state providers. Different policy levers may be needed to incentivize non-state providers to downsize or close facilities for seven or more people.

- States that operate large state-run IDD facilities should be encouraged to use available Medicaid rebalancing and other incentives to downsize or close those facilities and to provide supports for people with IDD in home and community-based settings instead.

- The seventeen states that have already closed all large state-run IDD facilities have found ways to support all people with IDD regardless of age or type or intensity of support needs in home and community-based settings. Policy initiatives and technical assistance efforts should help the remaining states to do the same.

Resources

- Residential Information Systems Project https://risp.umn.edu/
- 30 years of Community Living https://acl.gov/30years
- IMPACT newsletter (https://ici.umn.edu/series/14)
- ACL's Housing and Services Resource Center https://acl.gov/HousingAndServices
- Charting the Lifespan for Families of Individuals with Intellectual or Developmental Disabilities (Michelle Reynolds) https://supportstofamilies.org/

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