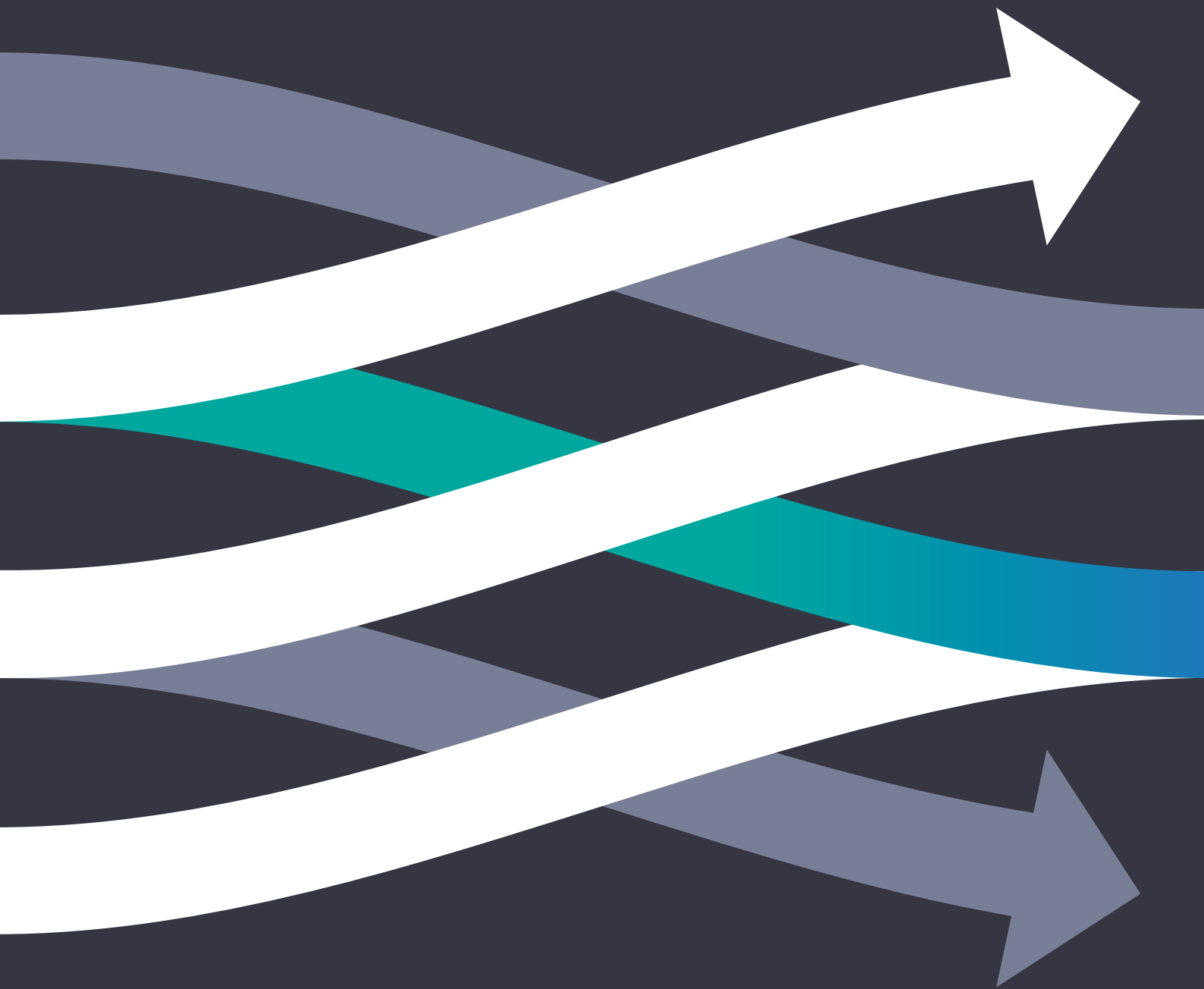


# I/DD Data Digest 2015

A collection of infographics presented by:





It is with great pleasure that MediSked and The Arc of the United States present the 2015 Data Digest – a compilation of the latest statistics on I/DD services and supports, all displayed in an easy to read infographic format.

The partnership between MediSked and The Arc has strengthened in recent years and this Data Digest illustrates the beauty of a technology company working with an advocacy organization to give data context and educate our industry on the current state of affairs in I/DD services and supports.

The need for more and better data is only growing and we hope that this publication provides important information and good insight. We have also included an interactive worksheet at the end of the Data Digest. You are encouraged to use it to fill out statistics for your own state. Just follow the links provided to get the data you need. We hope you find this to be a useful tool!

MediSked continues to push the boundaries of technology to improve the quality of life, personal outcomes and choices for the people 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 intellectual and developmental disabilities and their families. The organization continues to lead the way for a person-centered approach to supports and services.

Thank you!

A handwritten signature in blue ink that reads "Doug Golub".

Doug Golub

President, MediSked LLC

A handwritten signature in black ink that reads "Peter V. Berns".

Peter V. Berns

Chief Executive Officer, The Arc

# POPULATION & DEMOGRAPHICS



Approximately  
**53 million<sup>1</sup>**  
 Americans reported having a  
 disability in 2013.

Estimates of the number of people who have a cognitive disability are even higher when definitions include Alzheimer's, stroke, traumatic brain injury (TBI), severe and persistent mental illness, and intellectual disability (ID). Braddock & colleagues estimate that nearly 30 million people in the U.S. have a cognitive disability, of which 17% (over 5 million) have an ID.<sup>2</sup>

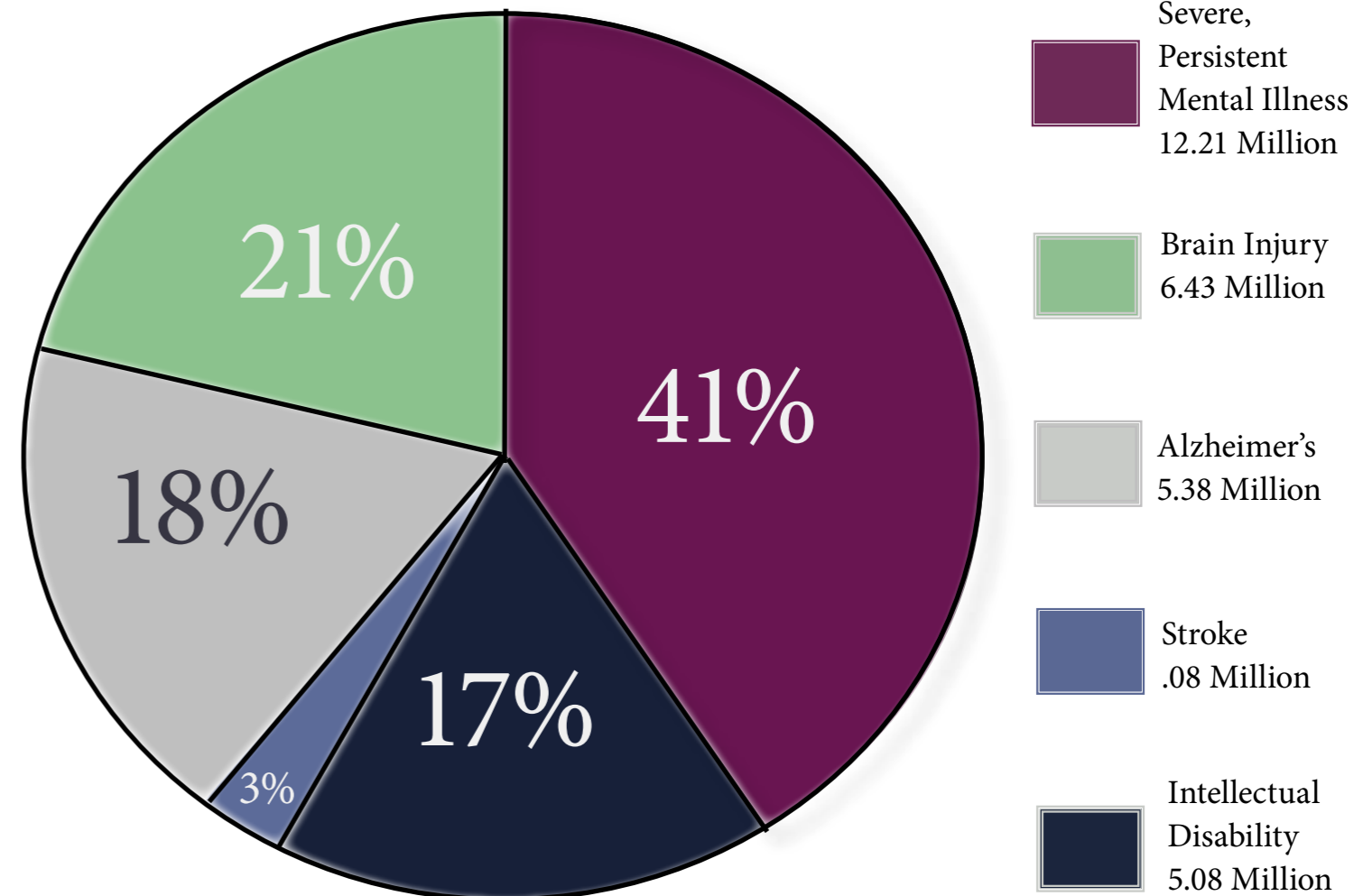
That equals



**1-in-5**  
 non-institutionalized  
 individuals over the  
 age of 18

or **22%**

## PREVALANCE OF COGNITIVE DISABILITY IN THE U.S. FY2013



of the 53 million+

3.6% Reported a **Self-Care Disability**

6.5% Reported an **Independent Living Disability**

10.6% Reported a **Cognitive Disability**

**Self Care Disability:** Survey respondents answered "yes" to the question "Because of a physical, mental, or emotional condition, do you have difficulty dressing and bathing?"

**Independent Living Disability:** Survey respondents answered "yes" to the question "Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?"

**Cognitive Disability:** Survey respondents answered "yes" to the question "Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?"

# WHERE DO PEOPLE LIVE?<sup>3</sup>



Today, more and more people are living



in the community



in smaller households

In 2012 there were 201,666 estimated state & non-state IDD residential settings in the U.S.



83%  
(166,764 settings)  
were for  
3 or fewer people

# 1.1 MILLION

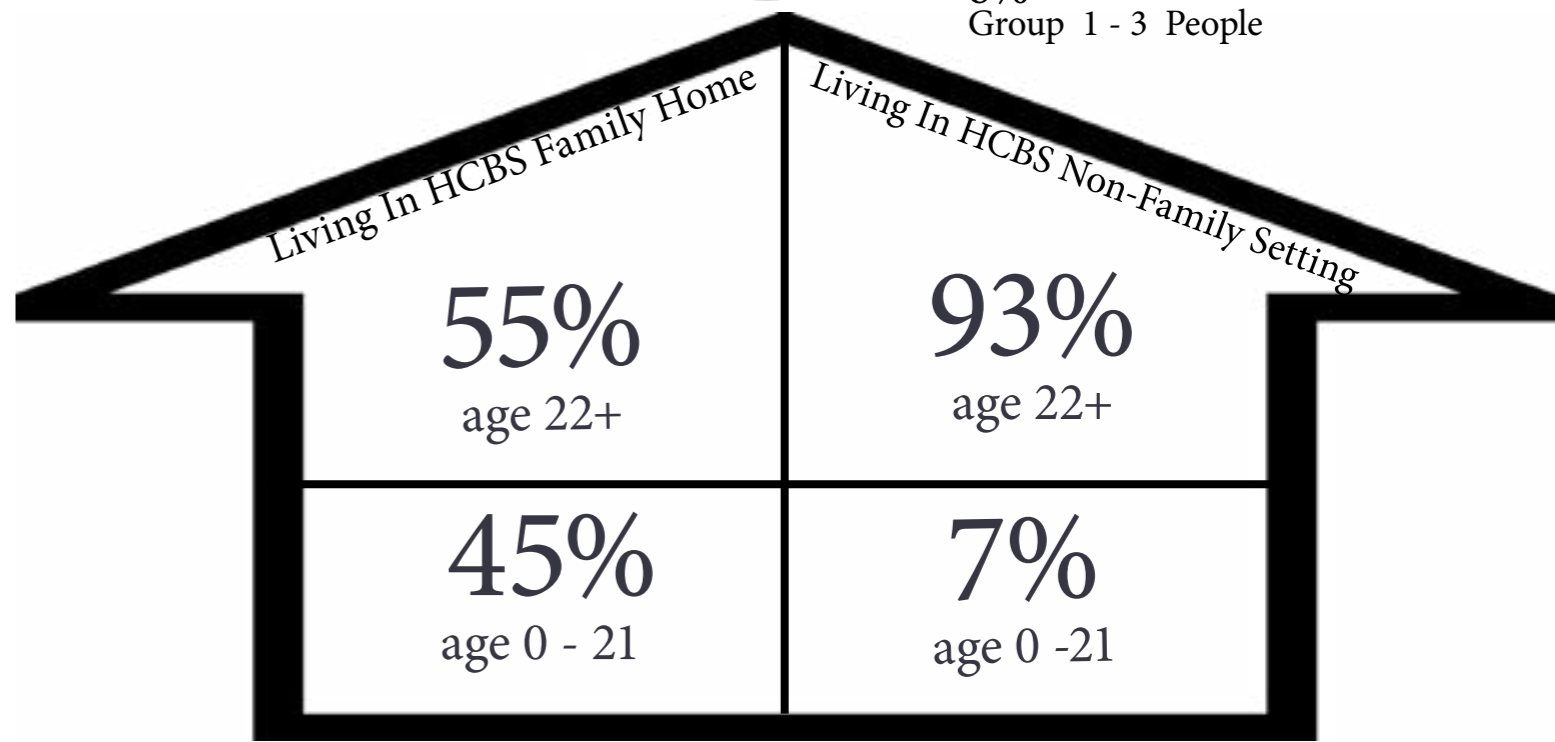
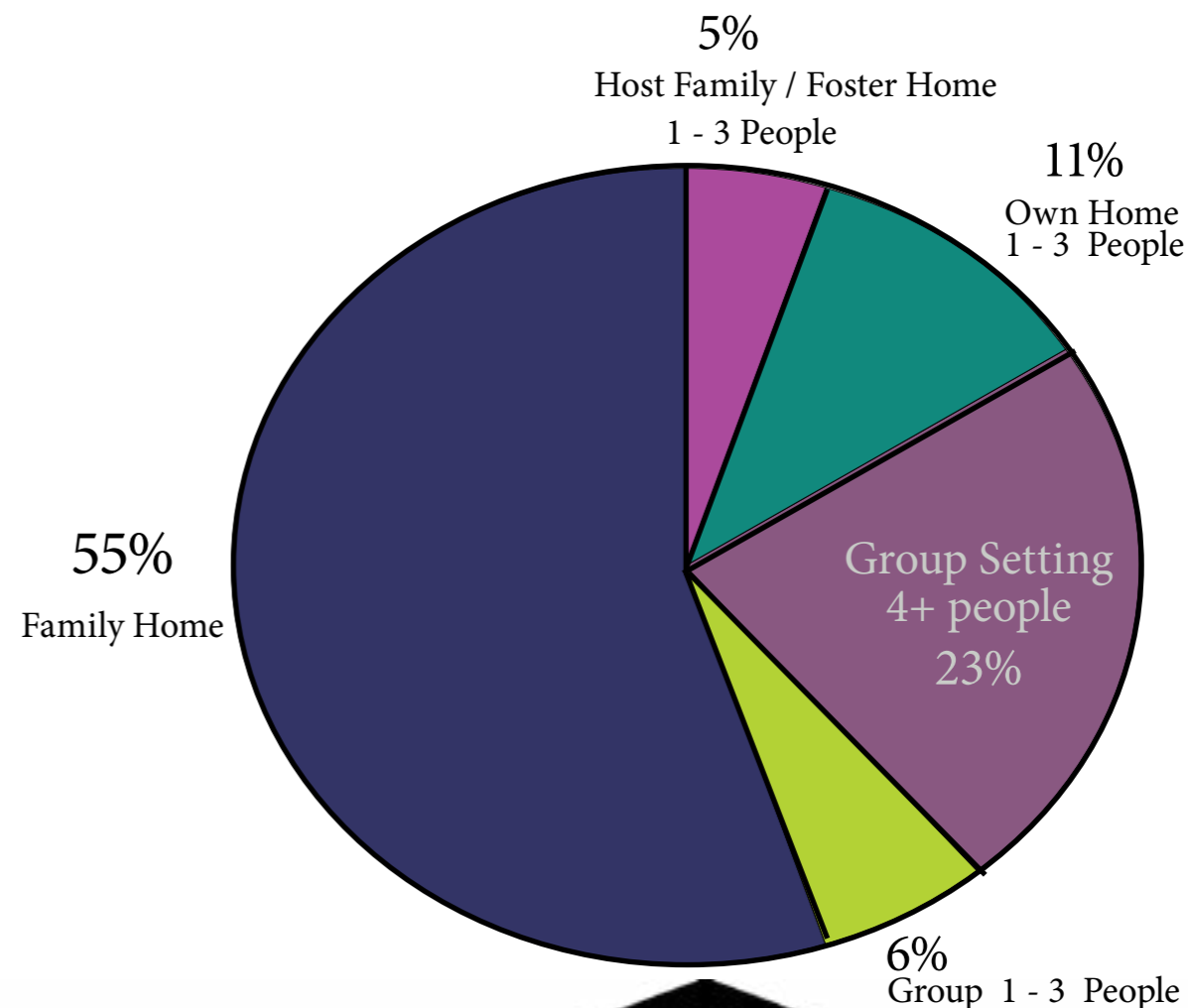
Individuals with IDD received formal services from an IDD agency

45%  
of people with IDD lived in a residential setting other than the family home in 2012



## Estimated Number of People with IDD in Individualized versus Congregate Settings as of June 30, 2012.

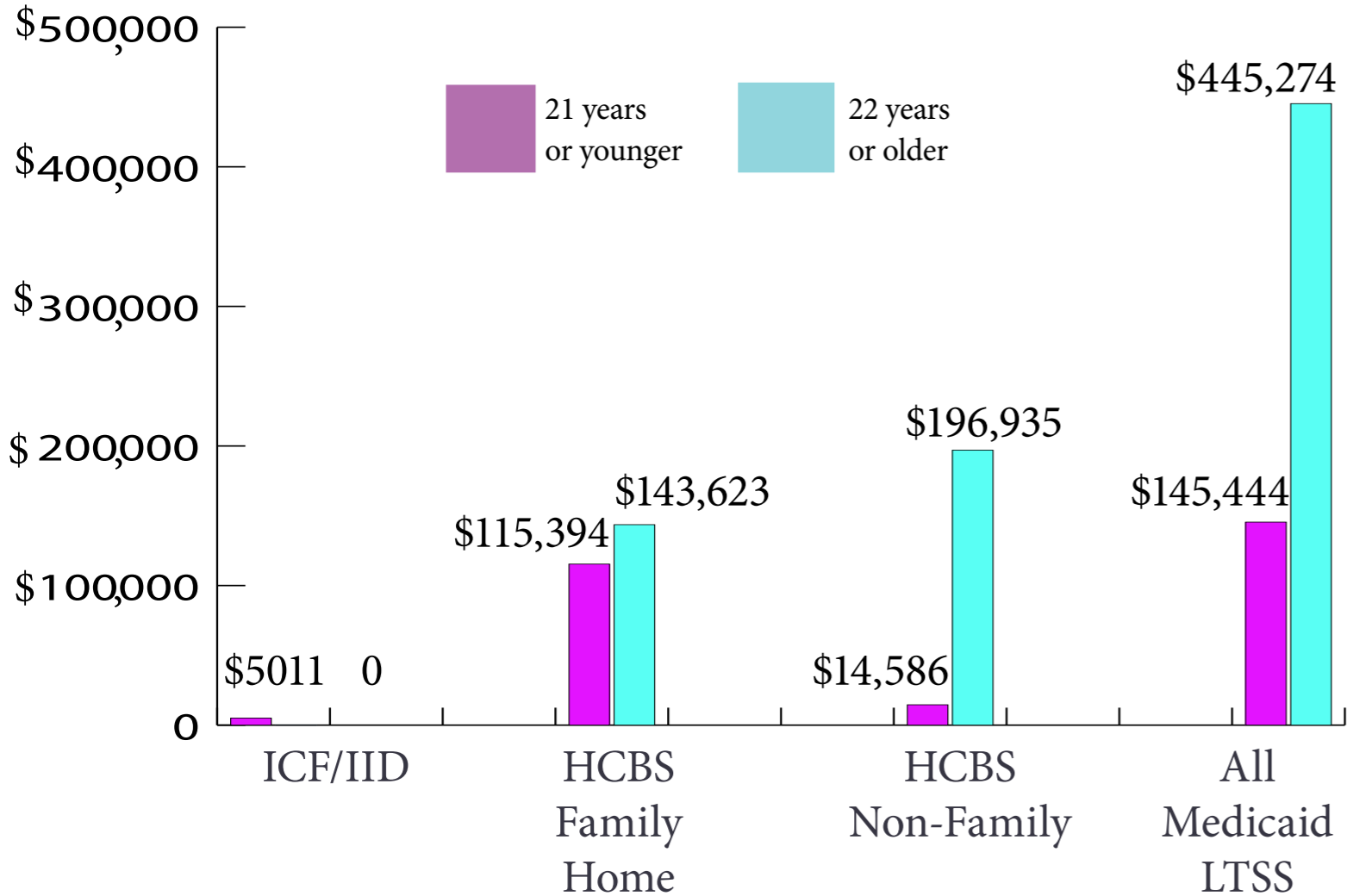
Reproduced with permission from the Research and Training Center on Community Living Institute on Community Integration/UCEDD



# WHERE DO PEOPLE LIVE?

(Continued)

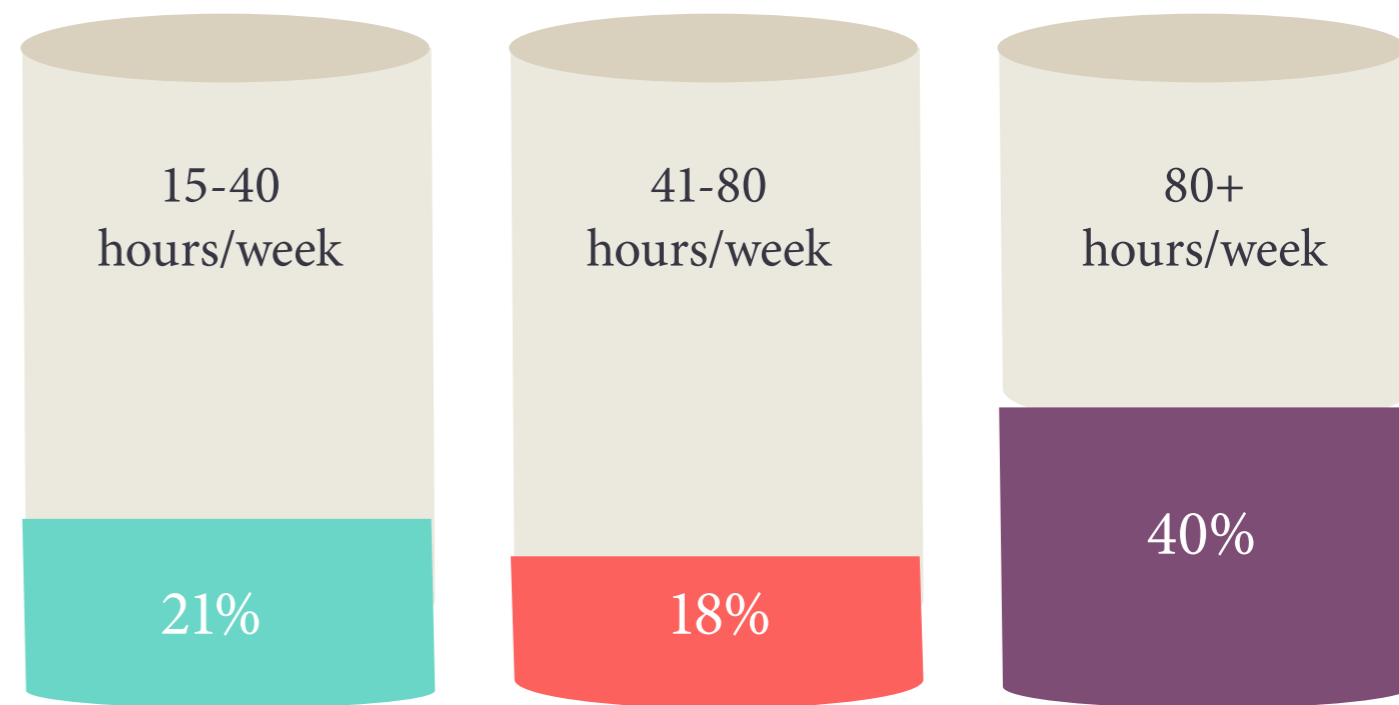
For recipients over the age of 22, HCBS Waiver funding is lower for family home settings than for non-family settings.



Reproduced with permission from the Research and Training Center on Community Living Institute on Community Integration/UCEDD

Additionally, the FINDS Survey indicated that of the family caregivers who responded:

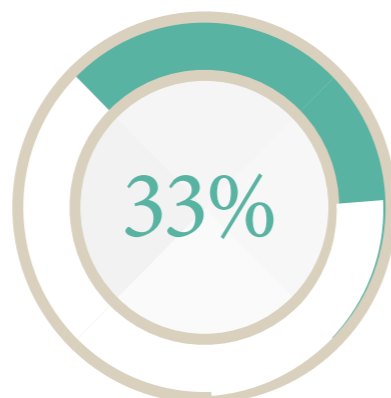
Hours of Support Provided Per Week<sup>4</sup>



The FINDS Survey<sup>4</sup> revealed that...



40% of family caregivers responded that their family member with IDD had unmet support needs



32% responded that their family member with IDD is on a waiting list for government funded services

**62%** of family caregivers indicated that they paid someone outside of the home for support during the previous month

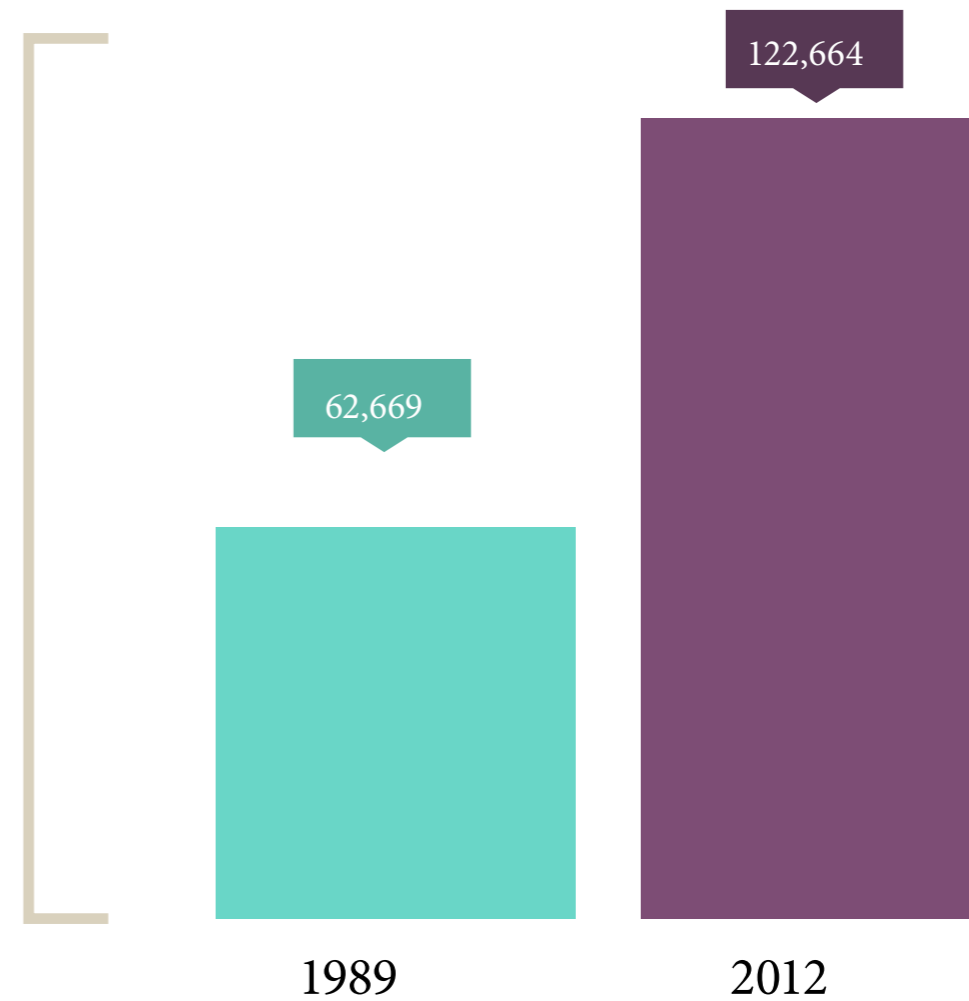


# WHERE DO PEOPLE LIVE?

(Continued)

Of the 473,802 people with IDD who do live in a more formal service setting, most (92%) live in a non-state operated system.

Between 1989 and 2012, the number of people with IDD who lived in a home that they owned or rented nearly doubled



**77%**  
of people who lived in a non-state IDD service setting in 2012 had five or fewer housemates.

**67%**  
(240,992 people)  
lived in individualized settings for 3 or fewer residents in 2012

According to The Arc's FINDS<sup>4</sup> survey

**28%** of respondents believed the ideal living situation for their family member with IDD is an apartment or house owned by the individual.

# WHERE DO PEOPLE LIVE?

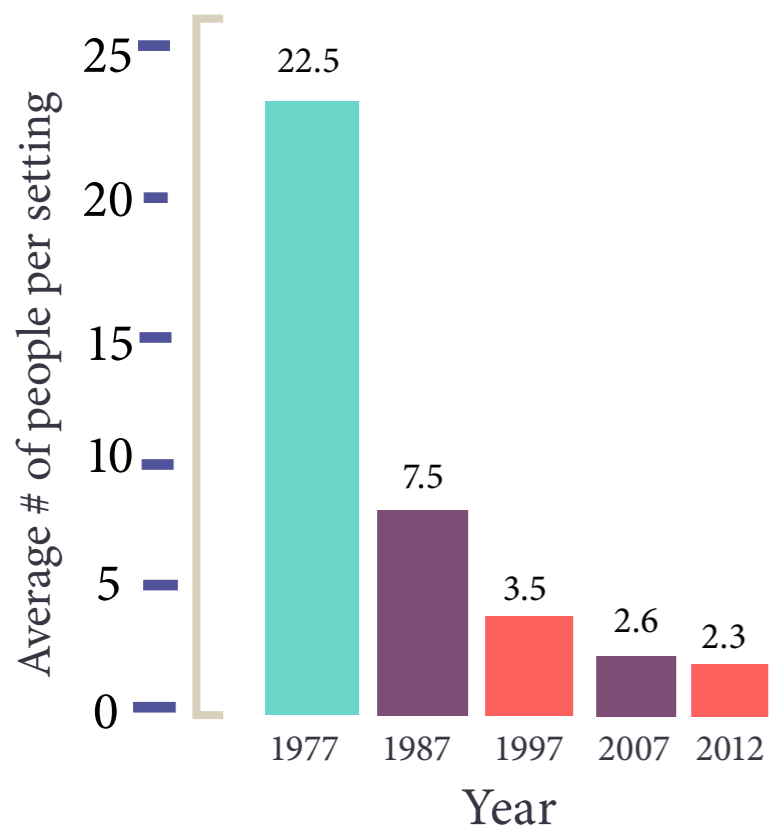
(Continued)

In 2014, the average monthly Supplemental Social Security Income payment nationally was \$750.00<sup>5</sup>



\$675 (or 90%) of that payment would be used to pay rent for an efficiency apartment.<sup>5</sup>

The average number of people living in an IDD setting has continued to decline since 1977

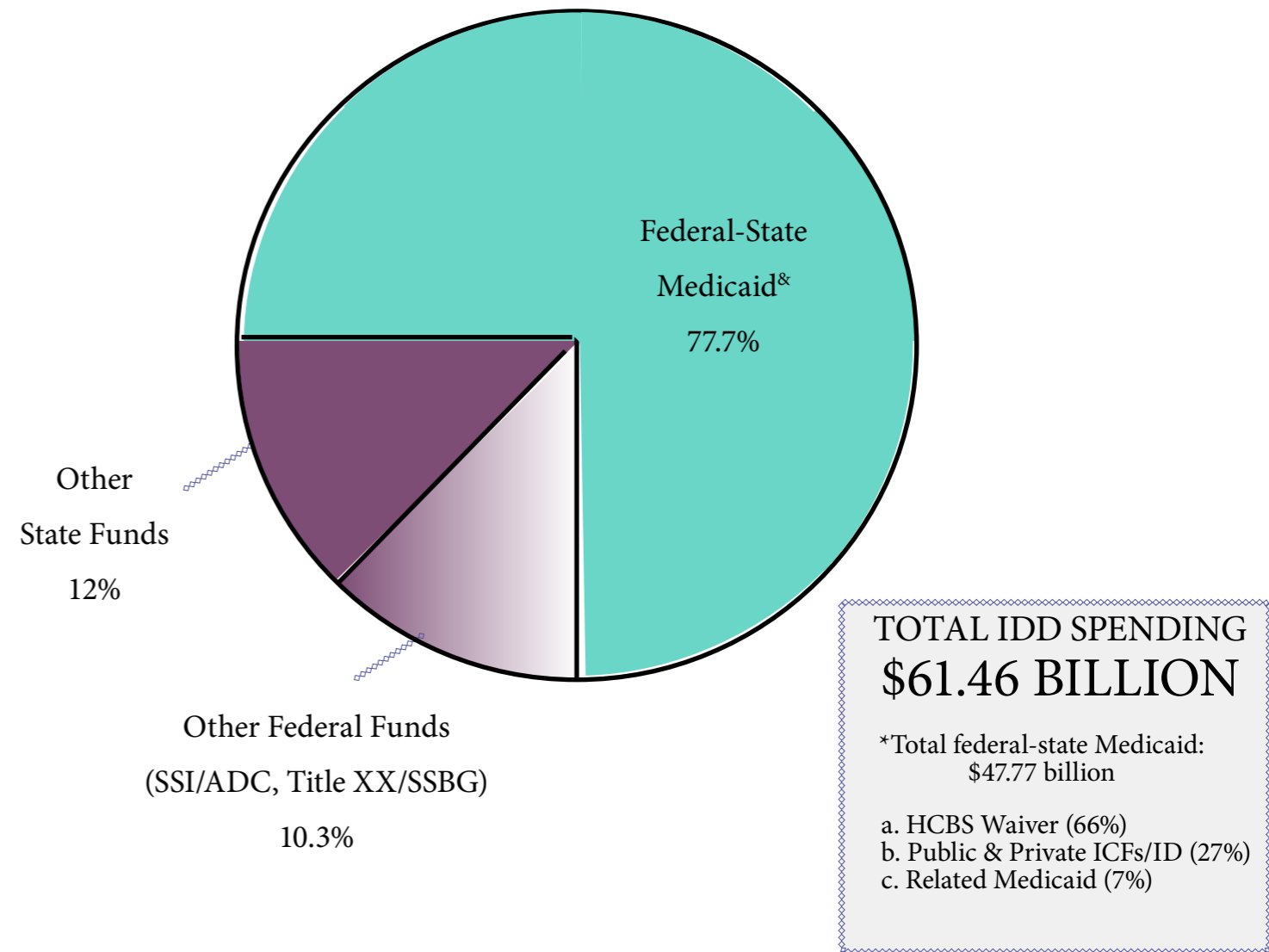


Source: Larson, S.A. et al (2014). In-home and residential long-term supports and services for persons with intellectual and developmental disabilities. Status and trends through 2012. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration

## Financing of Supports and Services<sup>2</sup>

**MEDICAID** is the main funder of IDD services

Federal-State Medicaid Was the Majority Of Total IDD Spending in FY 2013



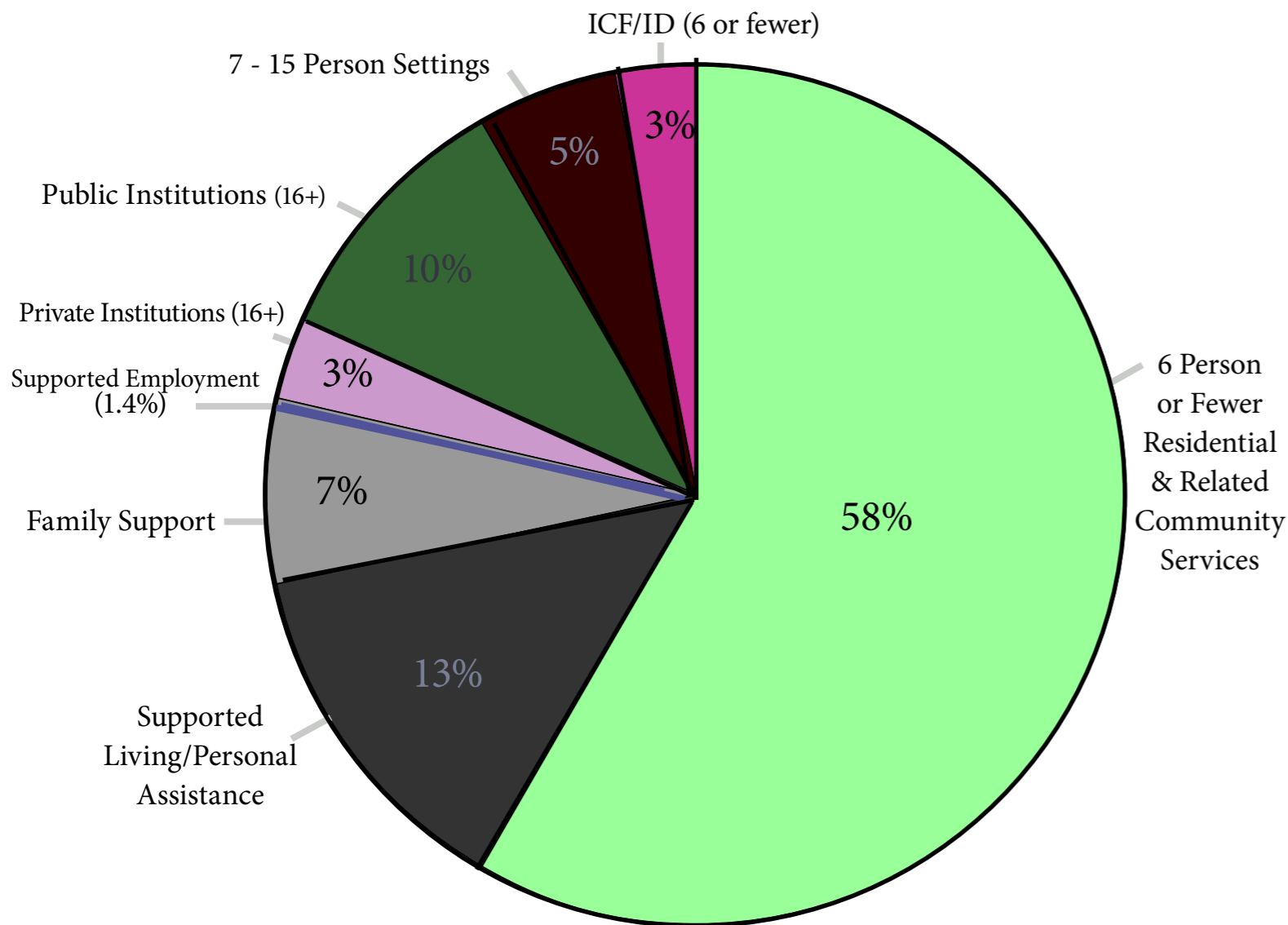
Source: Braddock et al, Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

# WHERE DO PEOPLE LIVE?

(Continued)

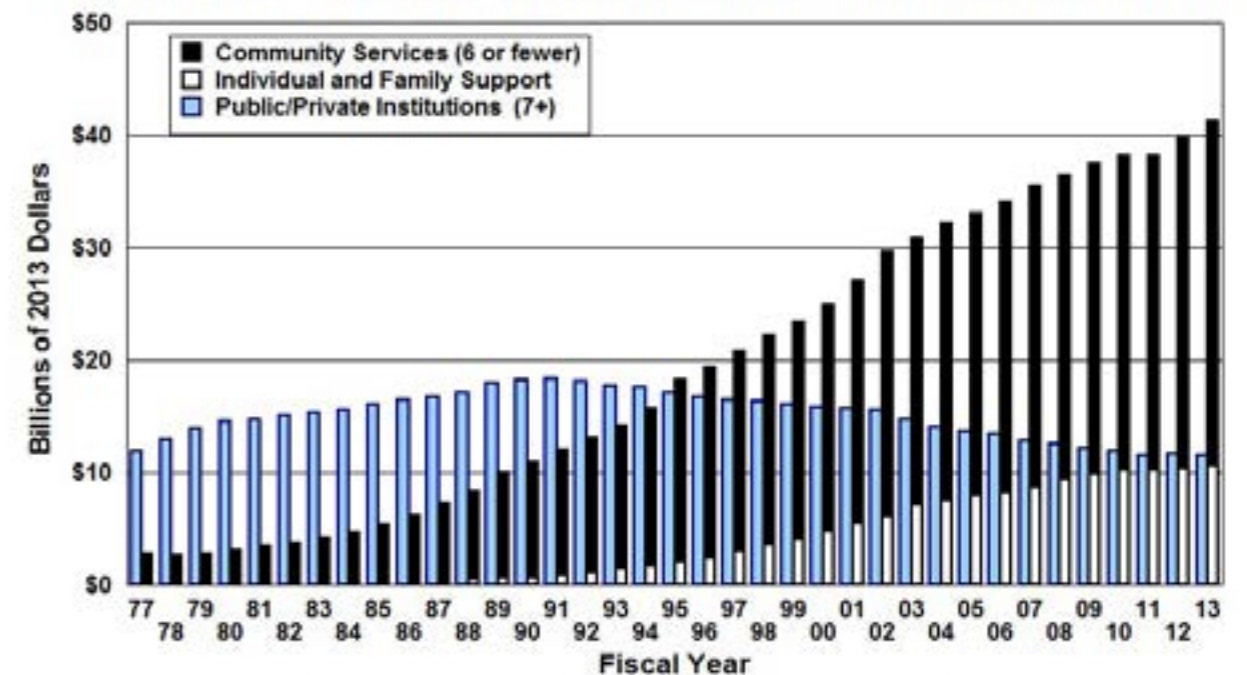
**58%** of Medicaid funding was spent on residential settings for six or fewer persons

Over the past few decades, there has been a shift in IDD funding: Spending on community services has increased while spending on institutions has decreased.



**\$61.46 BILLION**  
in total IDD spending

**Figure 6**  
**TRENDS IN I/DD SPENDING USING SIX OR FEWER PERSONS TO DEFINE COMMUNITY RESIDENTIAL SERVICES: FY 1977-2013**



(1) "Community Services" includes residential settings for 6 or fewer persons & day programs; (2) "Individual and Family Support," a subcomponent of community services, includes family support, supported living, personal assistance, and supported employment; (3) "Public/Private Institutions" serve 7 or more persons. Nursing facility spending is excluded.

Source: Braddock, et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.



# WHERE DO PEOPLE LIVE?

(Continued)

FY2013

\$254,905  
\$45,795

Average annual INSTITUTIONAL COST per person

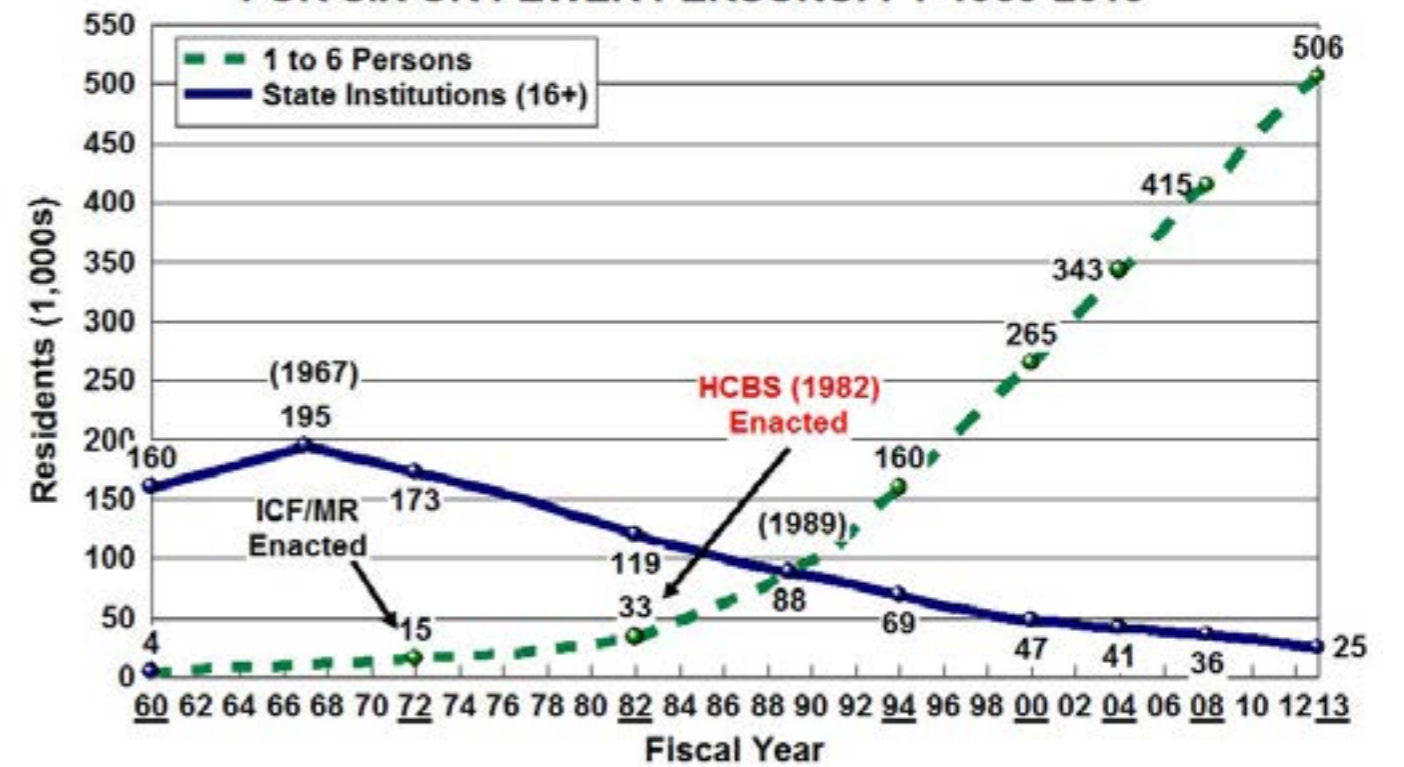
Average annual WAIVER COST per person

The total census of all institutions was highest in  
**1967**



Since the HCBS waiver was enacted, numbers of people with IDD living in community settings for six or fewer people has steadily increased.

**Figure 9**  
**NUMBER OF PERSONS WITH I/DD RESIDING IN SETTINGS FOR SIX OR FEWER PERSONS: FY 1960-2013**

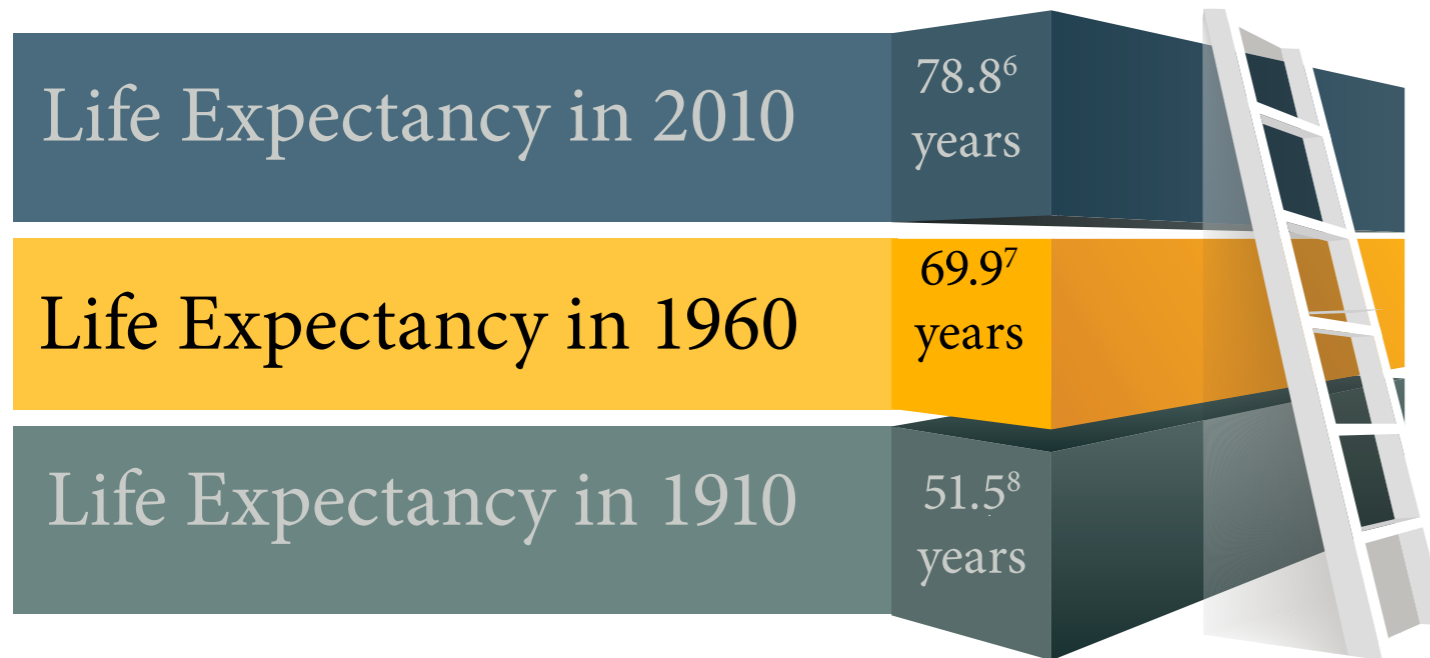


**Sources:** [1-6 person settings]: 1960-76 (computed from O'Connor (1976)); 1977-91 (Prouty, Smith, & Lakin, 2002); 1992-13 (Braddock, et al., 2015). [State Institutions]: 1960-76 (Lakin, 1979); 1977-2013 (Braddock et al., 2015).



# LIFE EXPECTANCY

A common indicator of the health of a population/nation is life expectancy. **In the U.S., the life expectancy (of both sexes and all races) at birth has increased 53% over the past 100 years**



## 3.56 MILLION

PEOPLE WITH IDD WHO LIVE WITH THEIR FAMILIES<sup>2</sup>

25% live with caregivers age 60+<sup>2</sup>



The aging of the baby boomers is an issue that demands attention



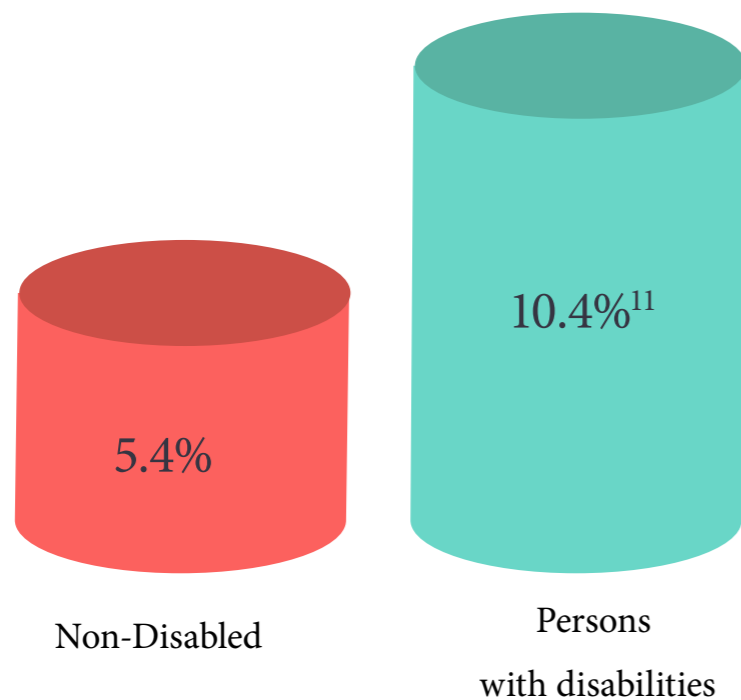
Despite well known health disparities<sup>9</sup>, people with intellectual disability (ID) are also experiencing increased longevity. In general, life expectancy of people with ID is approaching that of non-disabled peers.

## 62%

of respondents to The Arc's FINDS survey<sup>4</sup> indicated that they do not have a plan in place should the caregiver no longer be able to provide care.

# EMPLOYMENT

U.S. Unemployment Rate for  
Non-Institutionalized Civilians Age 16+ (July 2015)



# 62%

of FINDS survey respondents indicated a preference that people with I/DD work at a job in the community



In 2014...



7% of people receiving state IDD agency services were working in an individual job<sup>11</sup>



They worked an average of 27 hours every two weeks<sup>11</sup>



They earned an average of \$226.29 during that two week period<sup>11</sup>



This equals an average wage of \$8.38/hr

It is estimated that in FY2013



18.6% of people receiving services from an IDD state agency were participating in **integrated employment services**.



81.4% of people receiving services from an IDD state agency were participating in **facility-based non-work**.<sup>12</sup>

# 85%

of caregiver respondents reported that the adult with IDD for whom they provided support did not have a job.<sup>4</sup>



U.S. National  
Average Hourly  
Wage

\$22.71<sup>13</sup>

# SELF-DETERMINATION

# HEALTH

According to the National Core Indicators<sup>14</sup>



91% feel they have enough privacy at home



89% use the phone or internet without restriction



83% reported that they are able to go on dates



83% had input choosing their daily schedule



79% of people with I/DD surveyed reported they had a best friend



65% chose their staff



51% had input in choosing their home



45% had input in choosing their roommate



40% reported feeling lonely

According to the National Core Indicators<sup>14</sup>



7% chew or smoke tobacco



22% engage in regular physical activity (30 minutes of exercise 3x weekly)



33% are obese



55% take a psychotropic medication



78% received a flu vaccination in the past year



79% had a dental examination in the past year



95% of people with I/DD surveyed reported being in excellent or good health

In The Arc's FINDS<sup>4</sup> survey,  
**37% of respondents**

indicated that their family members with I/DD had a mental, psychological, psychiatric, or emotional impairment.



322,273  
PEOPLE



with IDD on a waiting list to receive waiver services under 1915(c) services, in 2013.

State/Local Chapter

[Find Chapter](#)

Residential Settings

[Get Info](#)

- # people living in state operated ICFs/ID (p 36)
- # people living in private ICFs/ID (p 36)
- # people living in homes for 6 or fewer (p 43)
- # people living in homes for 3 or fewer (p 43)

Medicaid/HCBS Funding

[Get Info](#)

# HCBS Waiver Participants

Average annual HCBS Waiver cost per participants (p 39)  
\$ / U.S. \$45,795

Average annual institutional cost per resident  
\$ / U.S. \$255,692

% Living in family home  
% / U.S. 71%

% Living with aging caregiver (age 60+)  
% / U.S. 25%

% of caregiving families receiving formal supports (p 60)  
% / U.S. 13%

Employment

[Get Info](#)

% of people receiving I/DD state services who are participating in integrated employment  
% / U.S. 7%

Average hours worked in a 2-week period  
/ U.S. 25.2

Average wage for 2-week period worked  
/ U.S. \$212.53

Housing

[Get Info](#)

SSI Average monthly benefit (p 23-39)  
/ U.S. \$750

Average cost of an efficiency apartment (p 41-2)  
/ U.S. \$675

Average cost of a 1-bedroom apartment (p 41-2)  
/ U.S. \$780

Waiting List

[Get Info](#)

Waiting list for HCBS Services

Helpful Resources

[UCEDD:](#)

[LEND:](#)

[DD Council:](#)

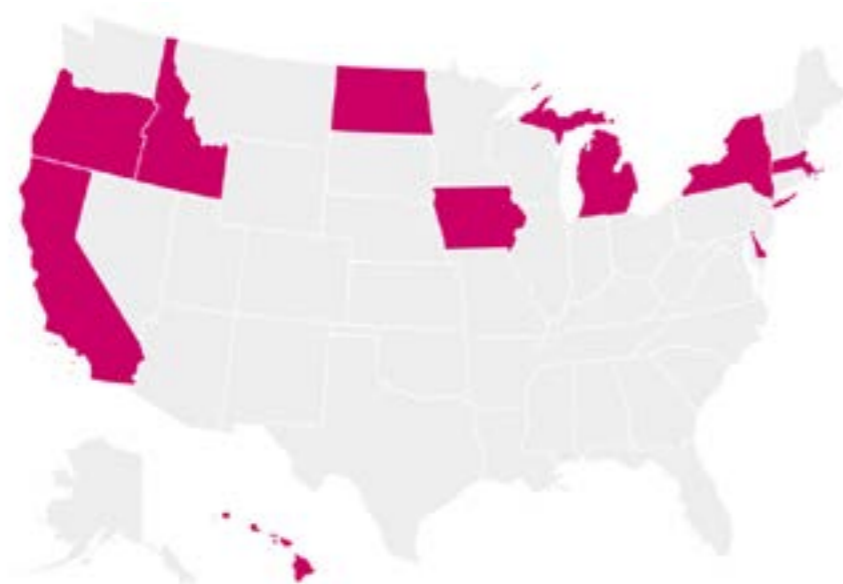
[P&A:](#)

[U.S. Senators:](#)

[U.S. Representative:](#)

11 STATES WITH NO WAIT LIST

- California
- Delaware
- Hawaii
- Idaho
- Iowa
- Massachusetts
- Michigan
- New York
- North Dakota
- Oregon
- Washington DC



GREATEST # OF PEOPLE WAITING FOR SERVICES

<b>TEXAS</b>	<b>OHIO</b>	<b>ILLINOIS</b>
<b>115,913</b>	<b>37,385</b>	<b>33,114</b>



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- <sup>4</sup> Anderson, L., Larson, S.A., & Wuorio, A. (2011). 2010 FINDS National Survey. Retrieved: <http://www.thearc.org/FINDS>
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