

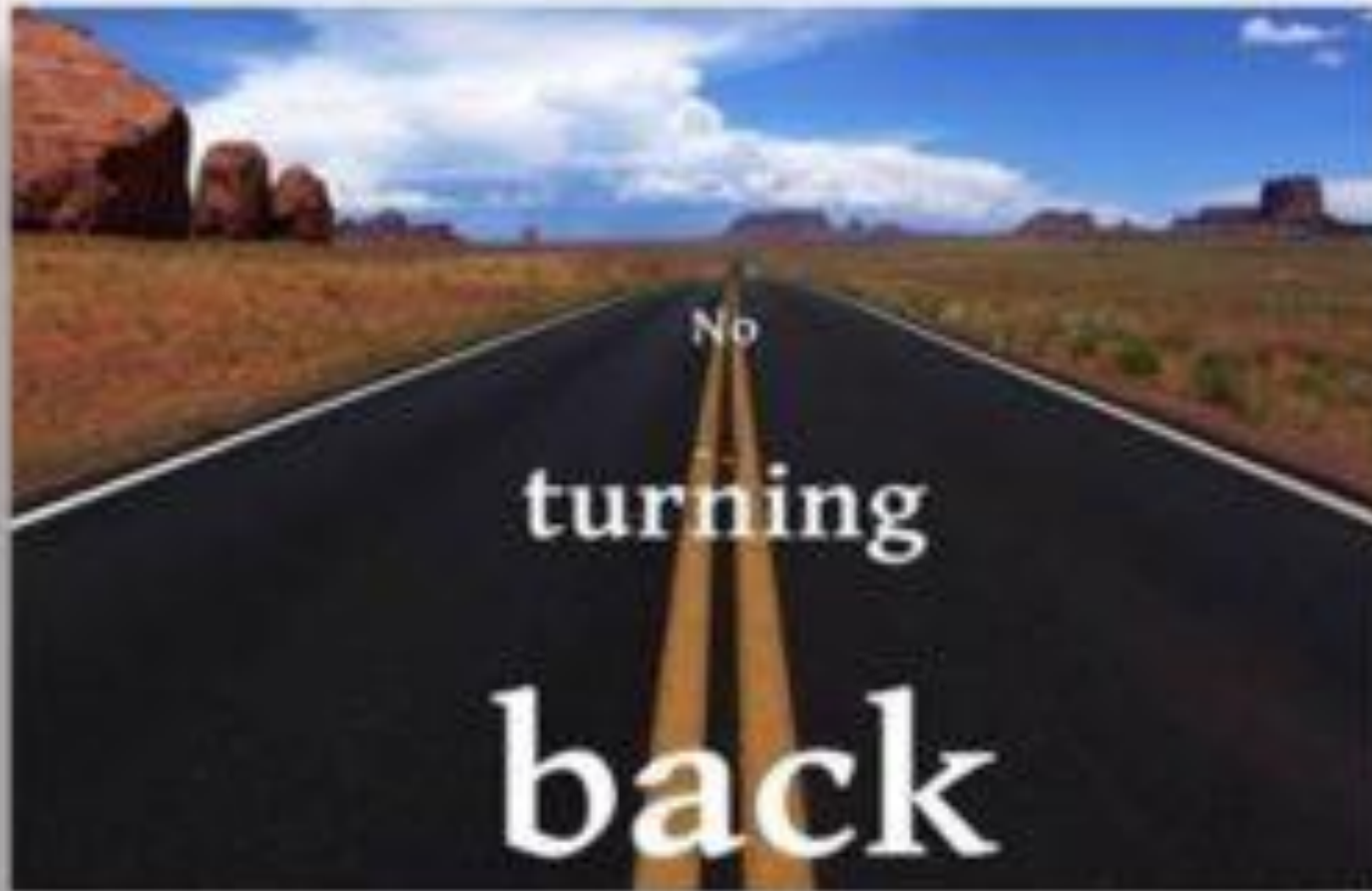
Best People. Best Solutions. Best Results.™

# Disability Trends Nationwide

Diane McComb  
Florida Quality Council  
November 2018

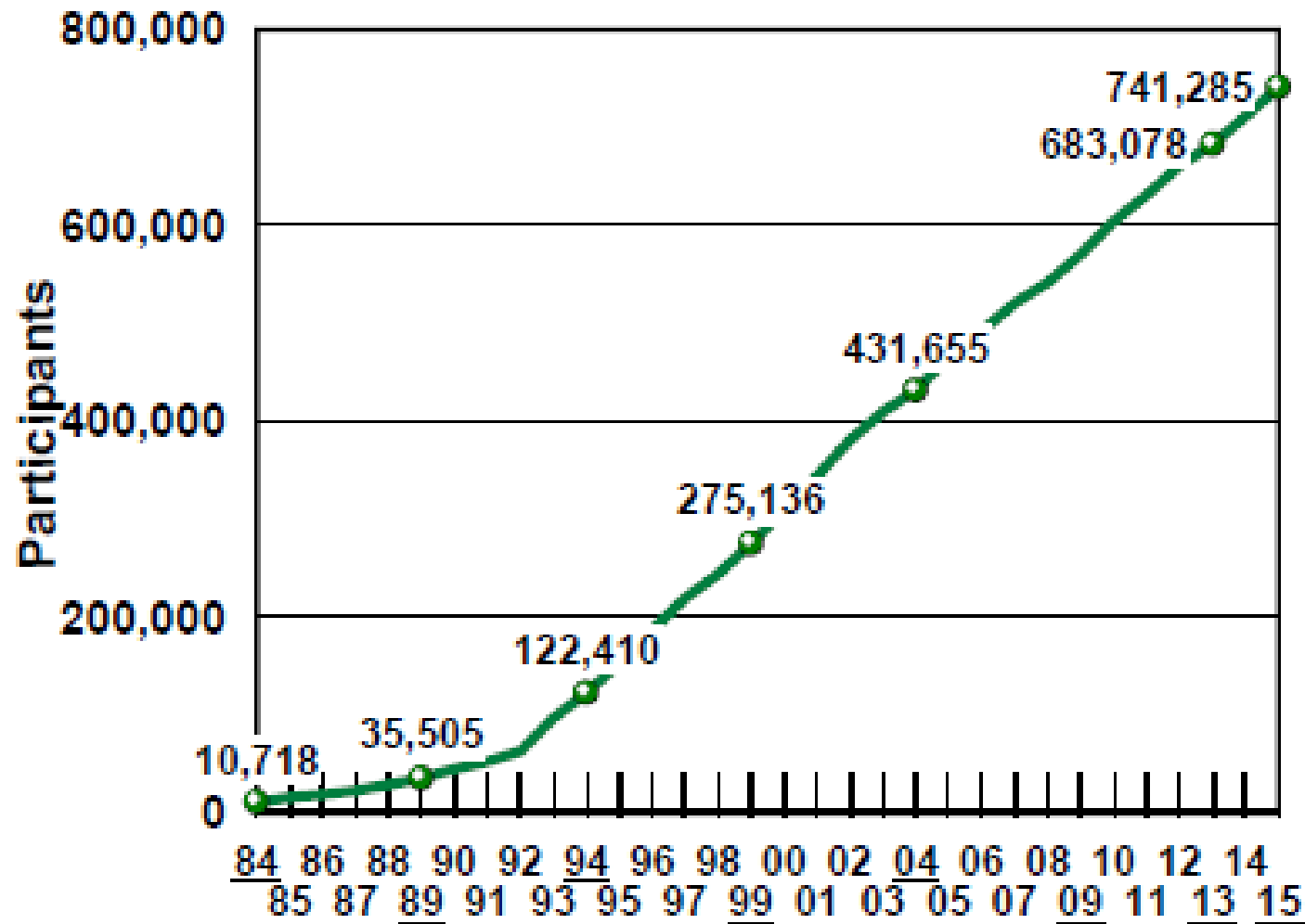
Qlarant 

The Future is Here, There is...



# Who do we serve?

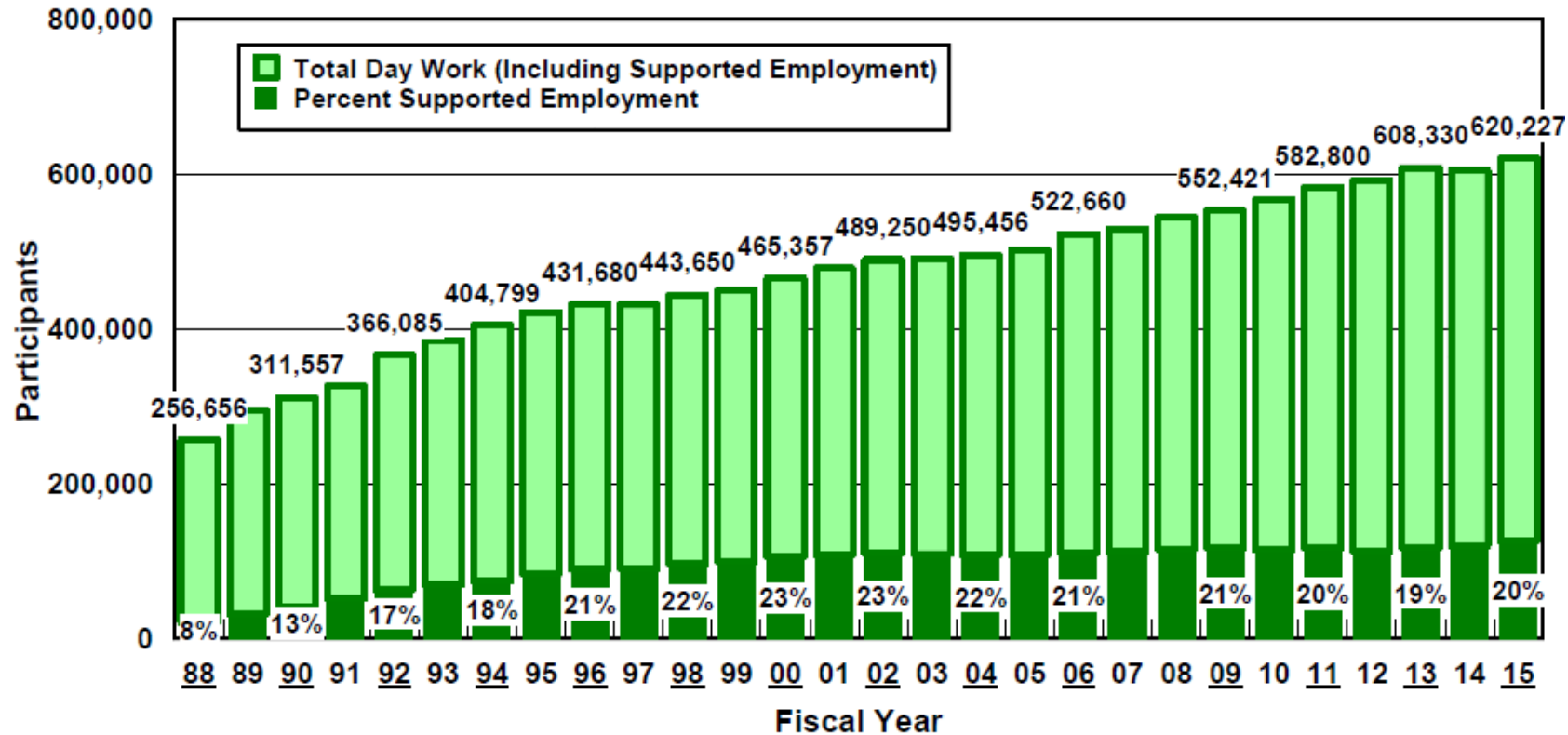
# People with IDD in Public System



Braddock, et.al., Coleman Institute and Dept. of Psychiatry, University of Colorado, 2017. <http://stateofthestates.org>

**Exactly what is it we do?**

**TOTAL DAY/WORK AND SUPPORTED  
EMPLOYMENT PARTICIPANTS : FY 1988-2015**

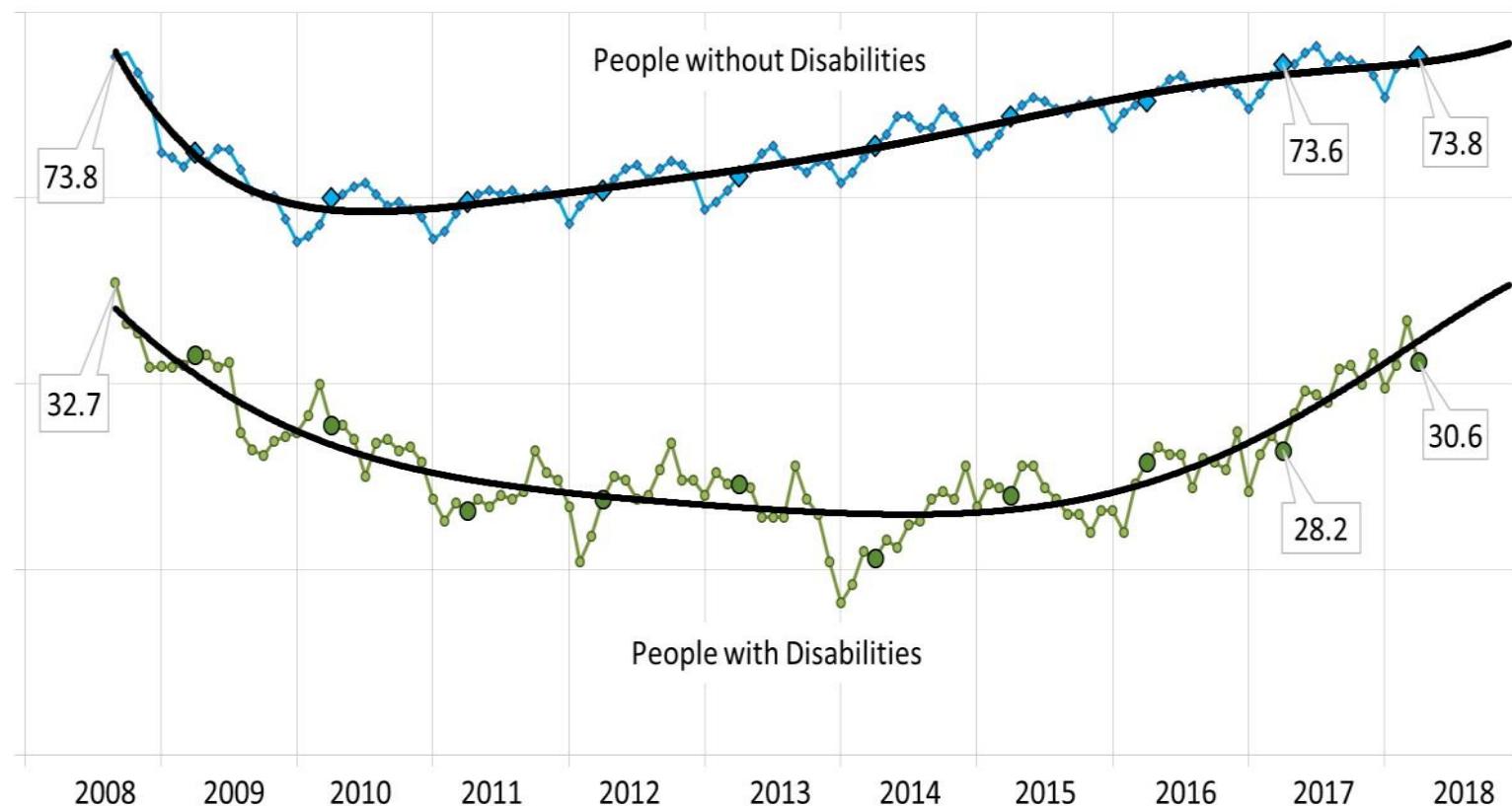


**We support 620,227 in all types of day services**

# Employment Trend – Positive Trajectory

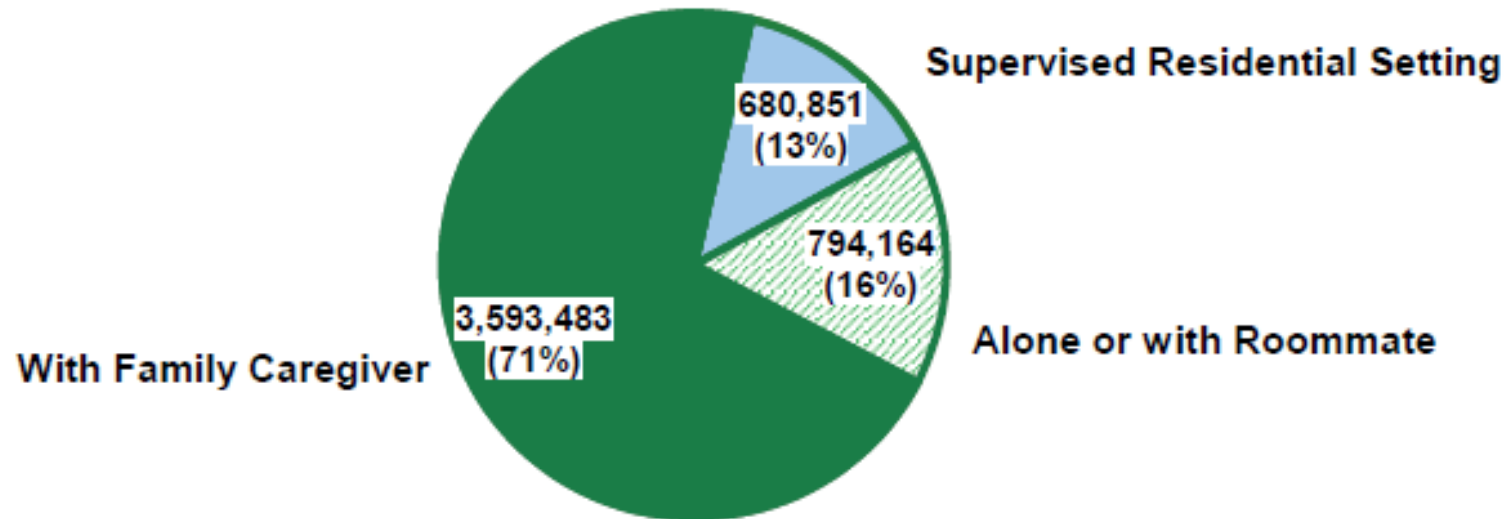
## Employment-to-Population Ratio

- Employers continuing to diversify their workforce
- People with disabilities tend to benefit from tight labor market



Source: U.S. Bureau of Labor Statistics, jobs report published May 4th. Kessler Foundation, Institute on Disability, University of New Hampshire.

## ESTIMATED NUMBER OF INDIVIDUALS WITH IDD BY LIVING ARRANGEMENT: FY 2015



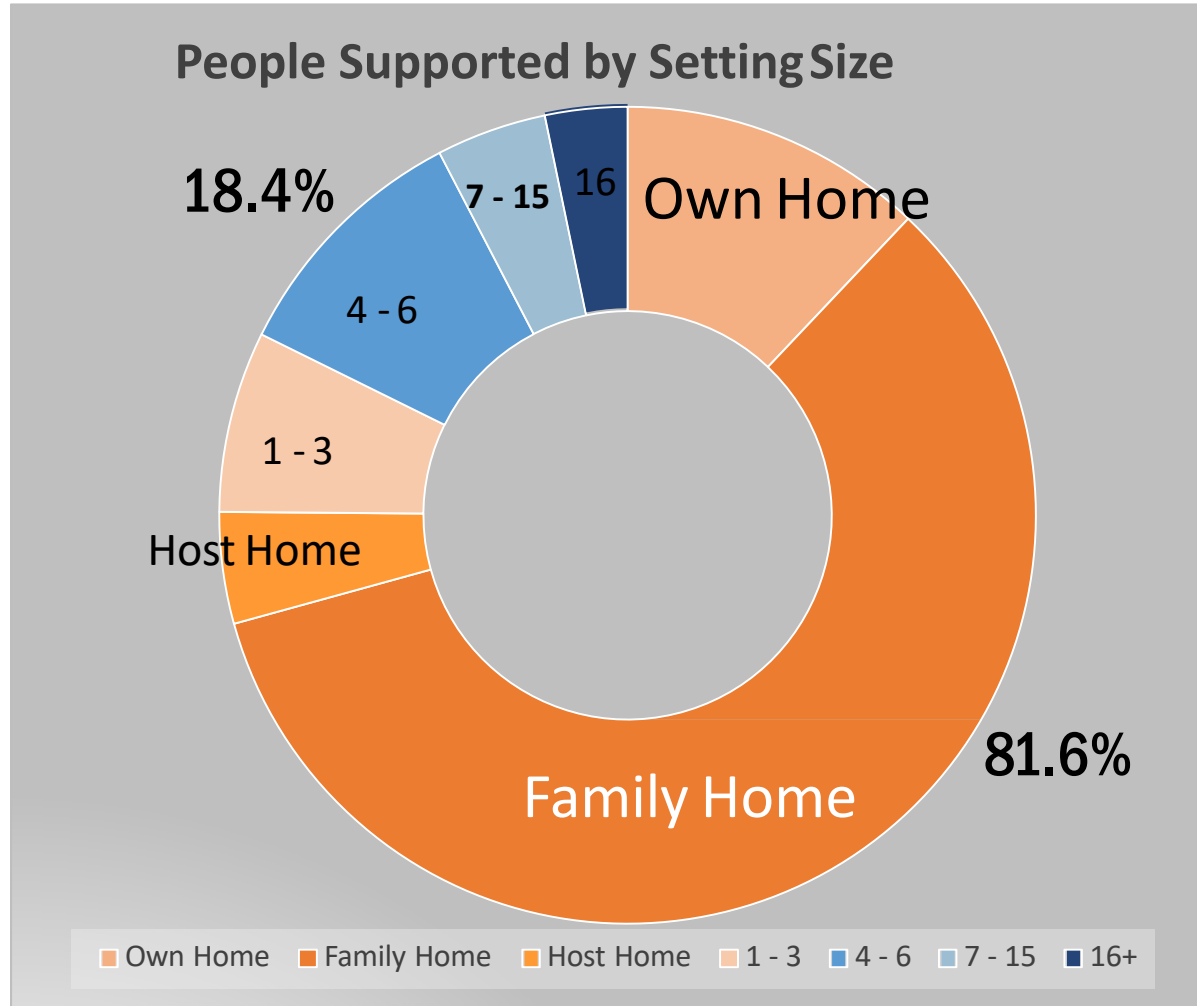
**TOTAL: 5,068,498 PERSONS**

Braddock et al. 2016, based on Fujiura 2008, 2012

Braddock, et.al., Coleman Institute and Dept. of Psychiatry, University of Colorado, 2016. <http://stateofthestates.org>



# Shift in Where People with I/DD Live



## Individualized Settings – 81.6%

- Own Home
- Family Home
- Host Home
- Group home 1 – 3 people

## Congregate Settings – 18.4%

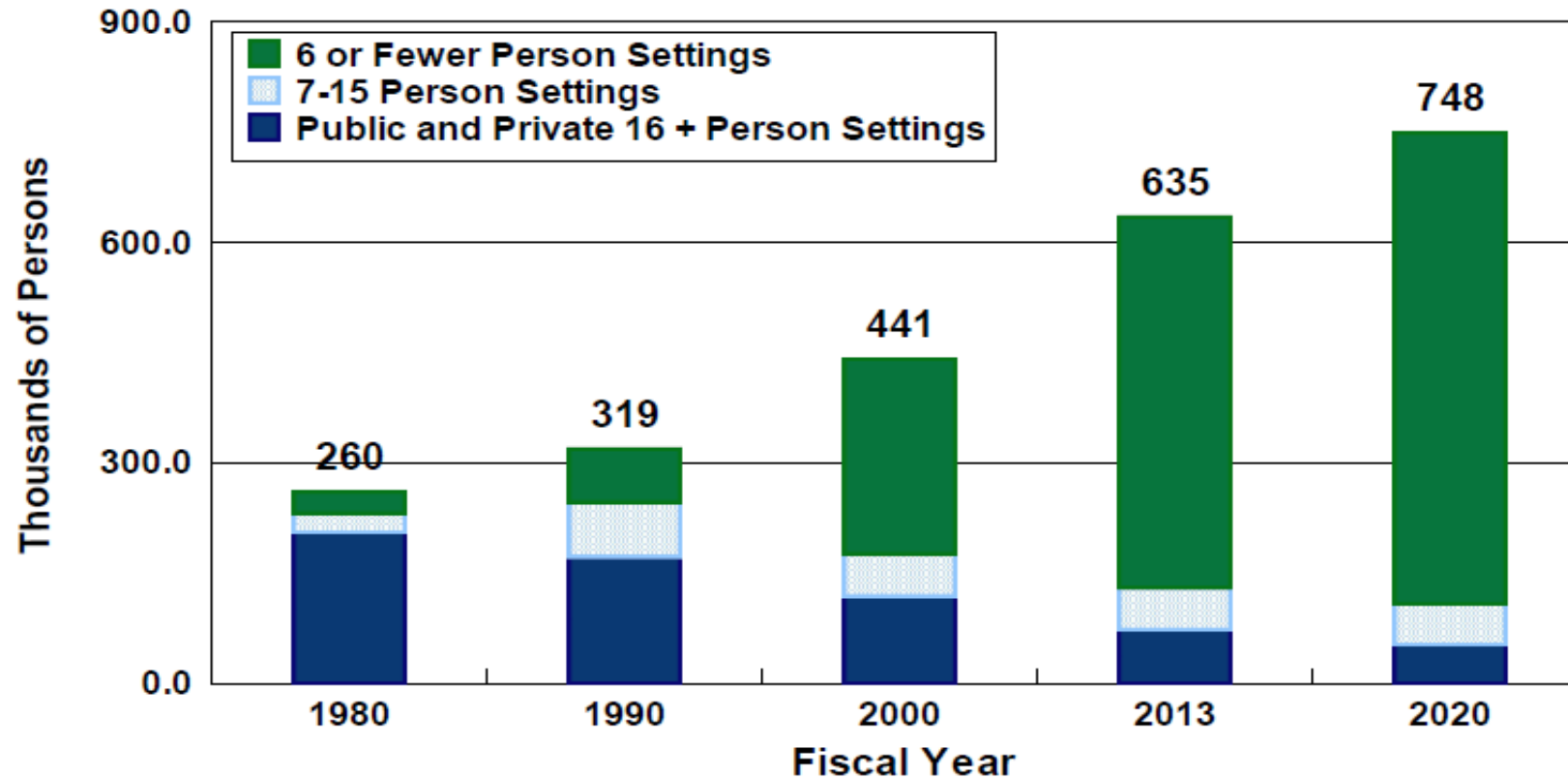
- Group home 4 – 6 people
- Group home 7 to 15 people
- Group home 16+

1,228,700 People Supported

\* University of Minnesota – 2016 RISP data

# Residential Growth Projection

***U.S. DEMAND FOR NEW I/DD RESIDENTIAL SERVICES IN 2020 IS 113,000 PERSONS WITH I/DD***

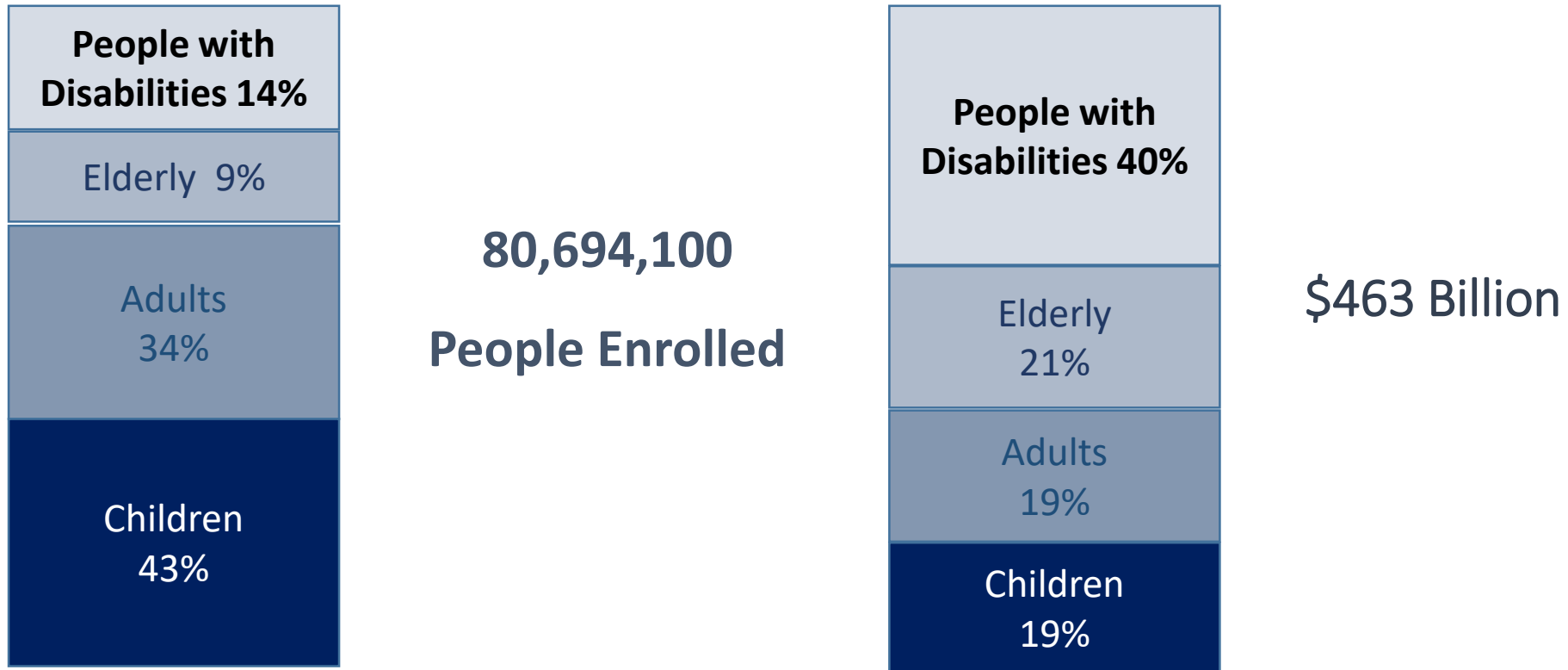


*2020 projected based on data from 2000-2013*

Source: Braddock, D. et al., *State of the States in Developmental Disabilities*, 2015 (preliminary).

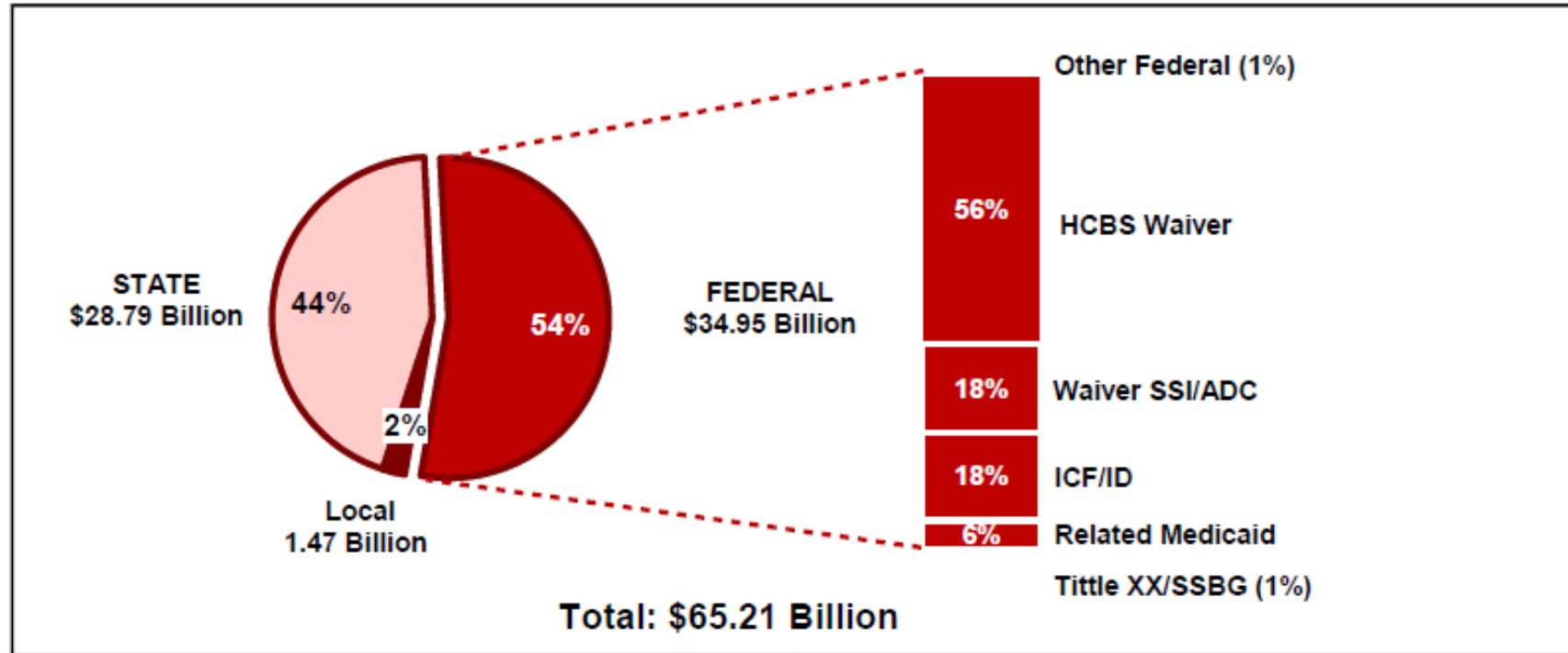
# What does it cost?

# People with Disabilities Account for the Largest Share of Medicaid Spending (2014 Kaiser Foundation)



<https://www.kff.org/medicaid/state-indicator/distribution-of-medicaid-enrollees-by-enrollment-group/?dataView=0&currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

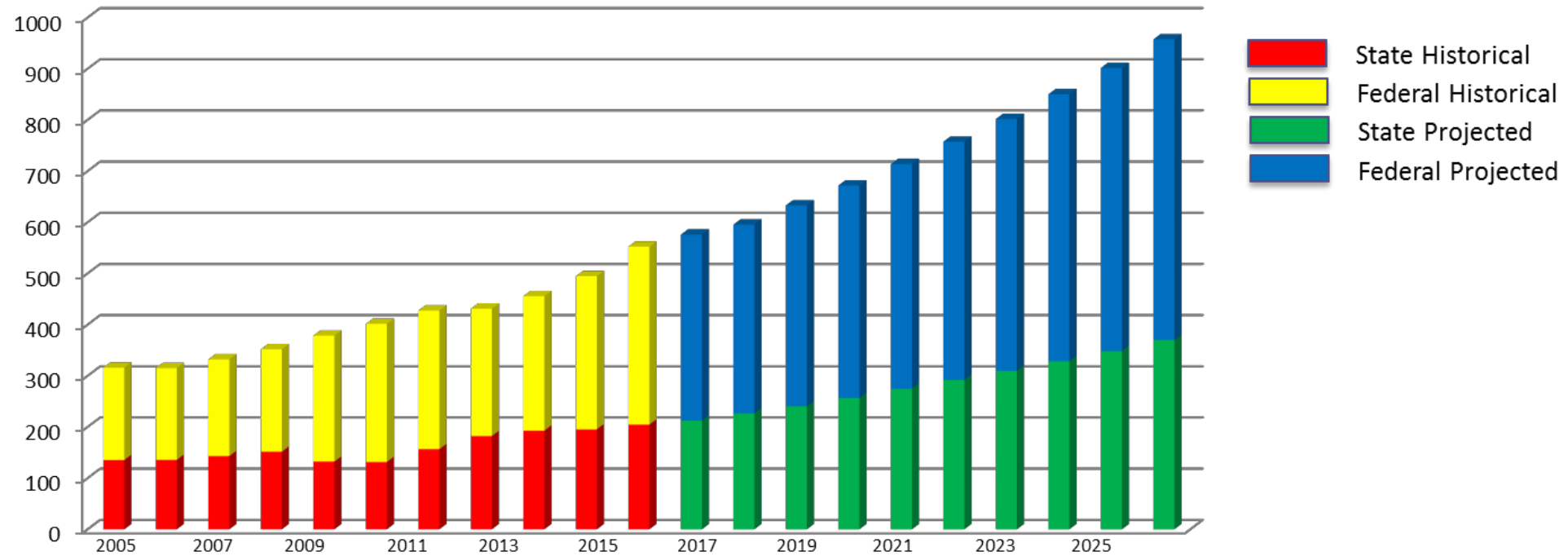
# \$65.21 Billion in Public Funds



Braddock, et.al., Coleman Institute and Dept. of Psychiatry, University of Colorado, 2015. <http://stateofthestates.org>

# Medicaid Spending Trends Are Unsustainable

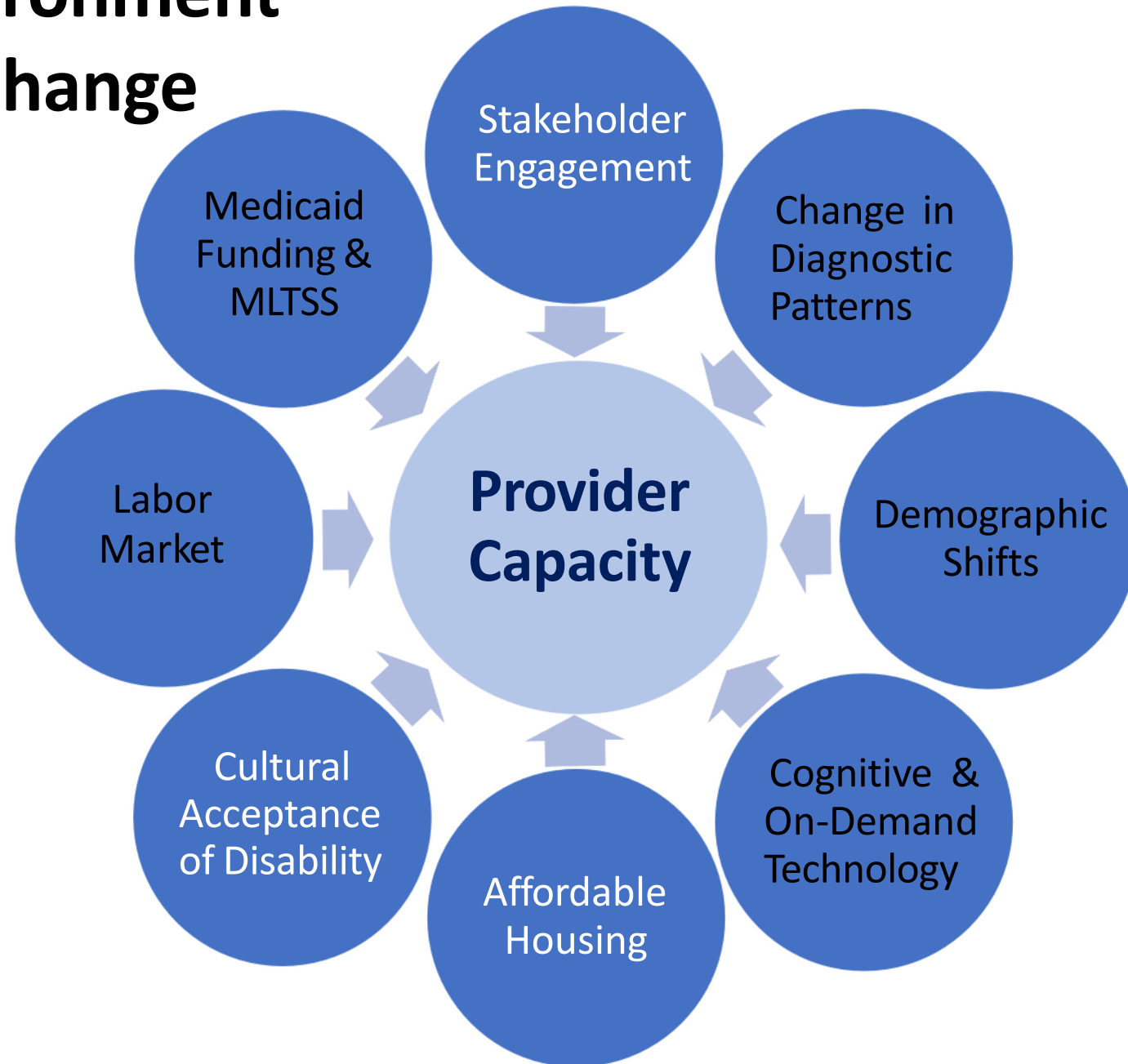
Average State and Federal Expenditures in Billions of Dollars



Source: Office of the Actuary, Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services, *2016 Actuarial Report on the Financial Outlook for Medicaid*, (Washington, D.C.: GPO, 2016), 15.

# So What's Different?

# External Environment Influencing Change

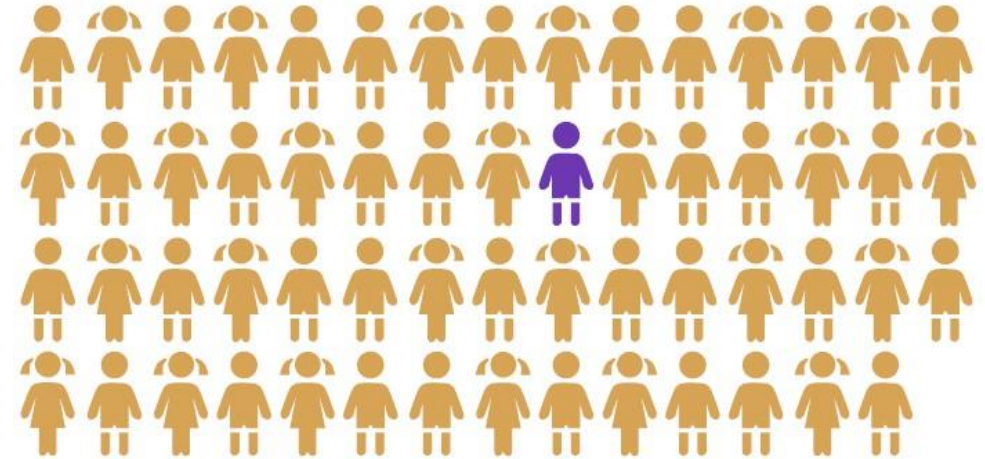




# Change in Diagnostic Patterns

Surveillance Year	Birth Year	Prevalence per 1,000 Children	About 1 in X children
2000	1992	6.7	1 in 150
2002	1994	6.6	1 in 150
2004	1996	8.0	1 in 125
2006	1998	9.0	1 in 110
2008	2000	11.3	1 in 88
2010	2002	14.7	1 in 68
2012	2004	14.6	1 in 68
2014	2006	16.8	1 in 59

## Diagnosis of Autism Spectrum Disorders



# 1 in 59

8-year-old children  
were identified with ASD  
by ADDM in 2014

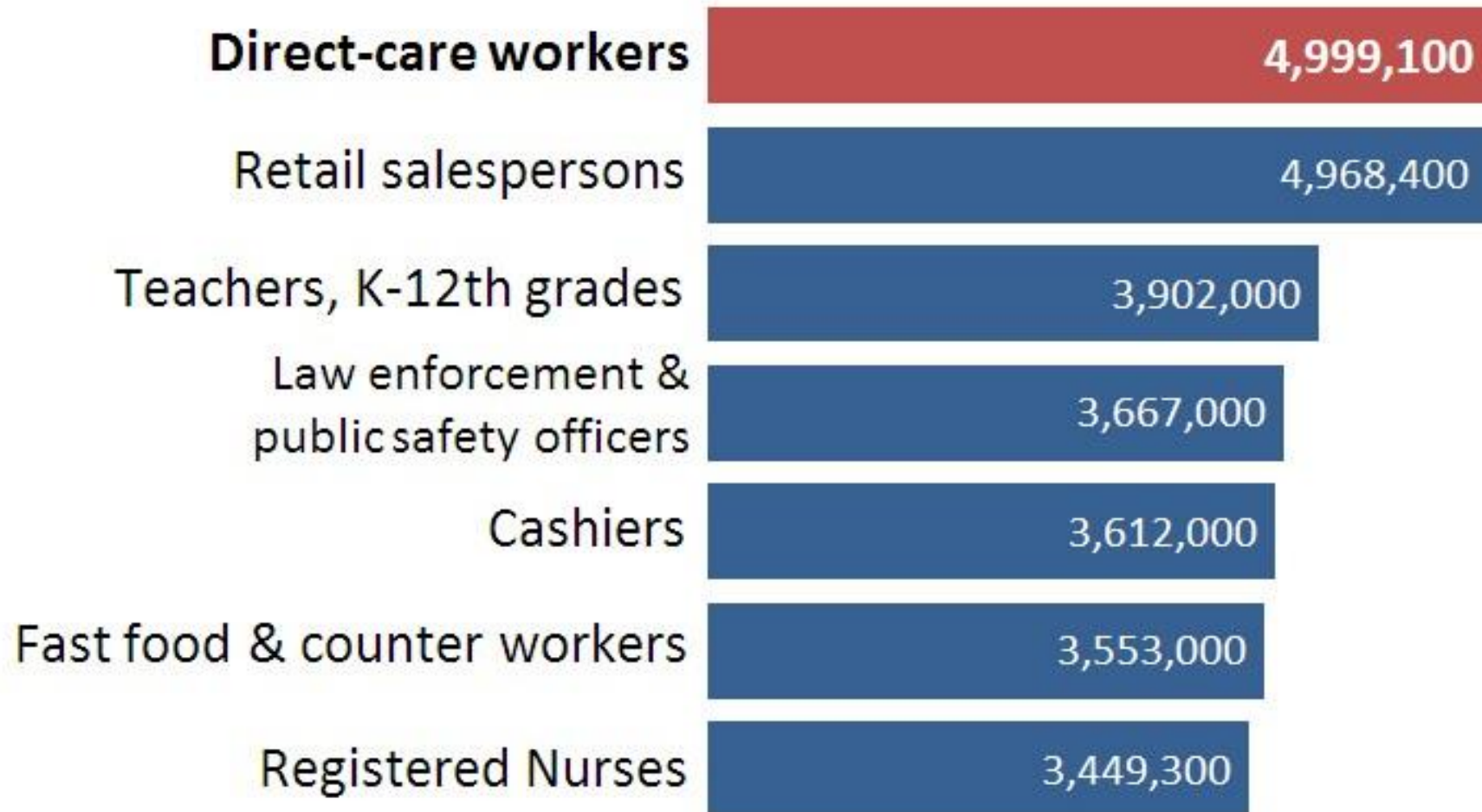
# Labor Market

- Workforce crisis – estimates through 2020
  - 1.2 million additional Direct Support Professionals (DSP) needed, a 37% increase
  - Labor force of adults between 18-39 expected to increase by only 7%
- State unemployment trends
  - National unemployment rate of 3.9%, April 2018
- State and municipal minimum wage laws
  - Municipal pressures in Seattle, New York, Minneapolis, Washington DC
  - Medicaid funding does not allow providers to increase rates to accommodate increases in minimum wage

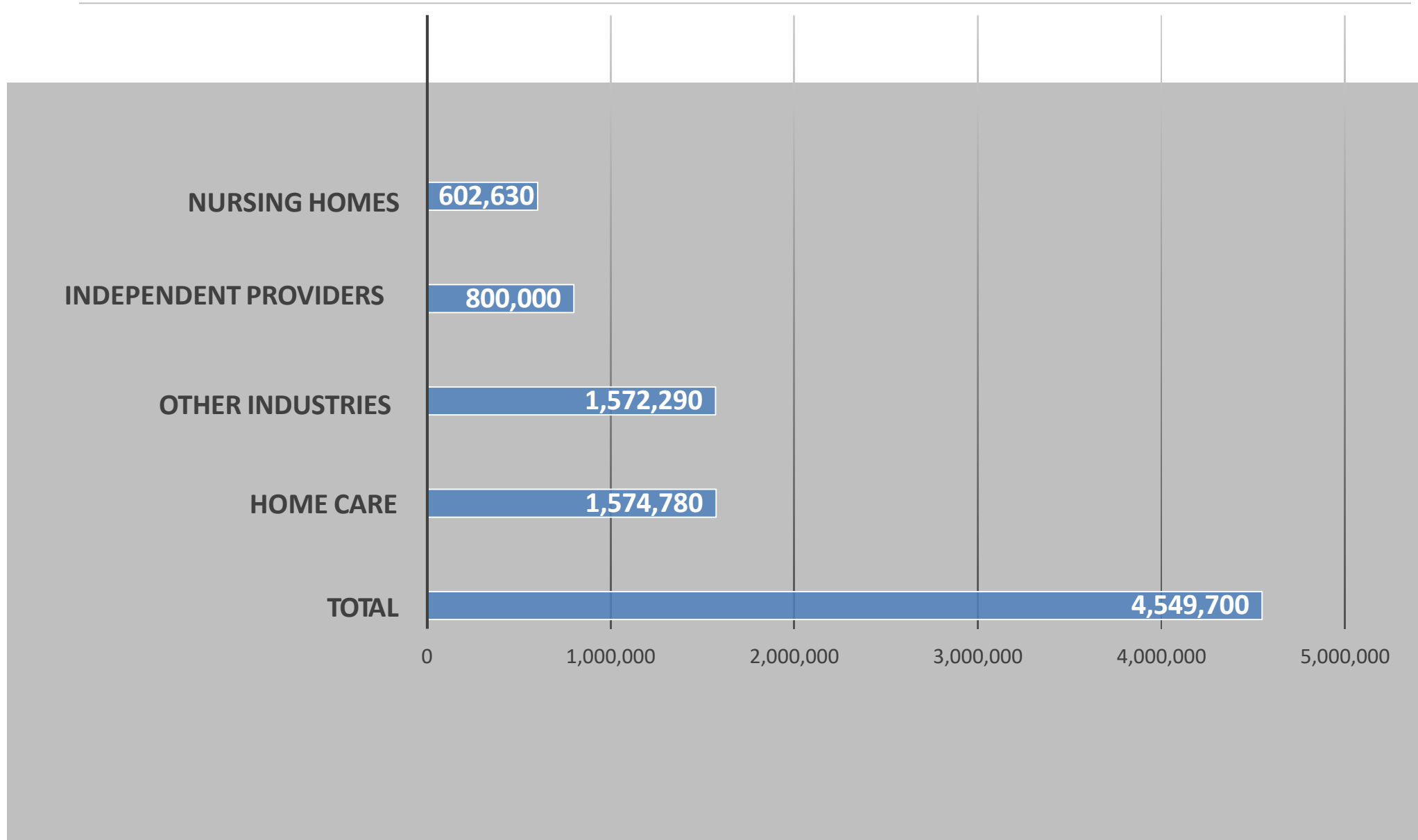
# Five Million Direct-Care Workers Needed by 2020



# Largest Occupational Groups in the US, 2020



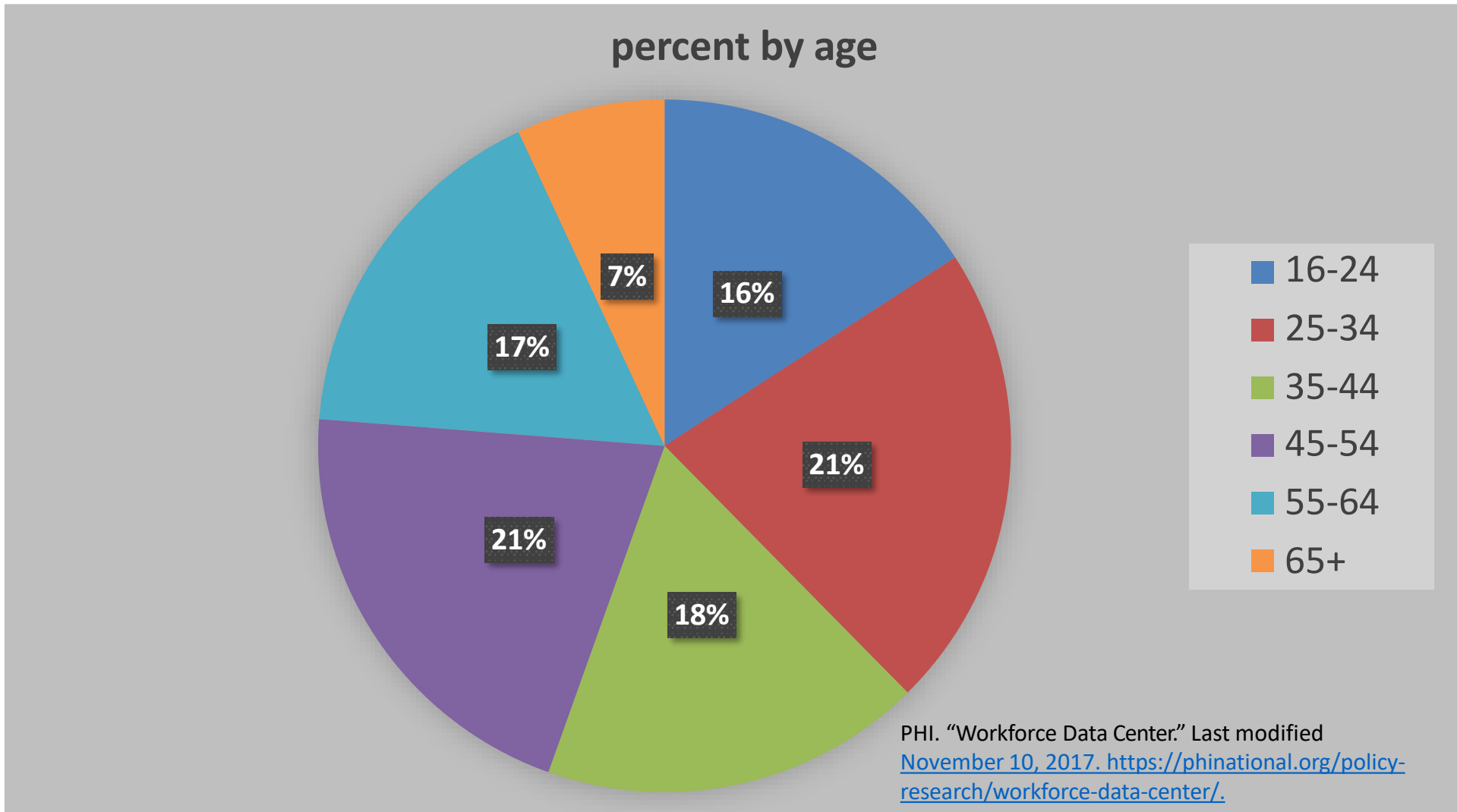
# Number of DSPs in US 2016



# Changing Demographics

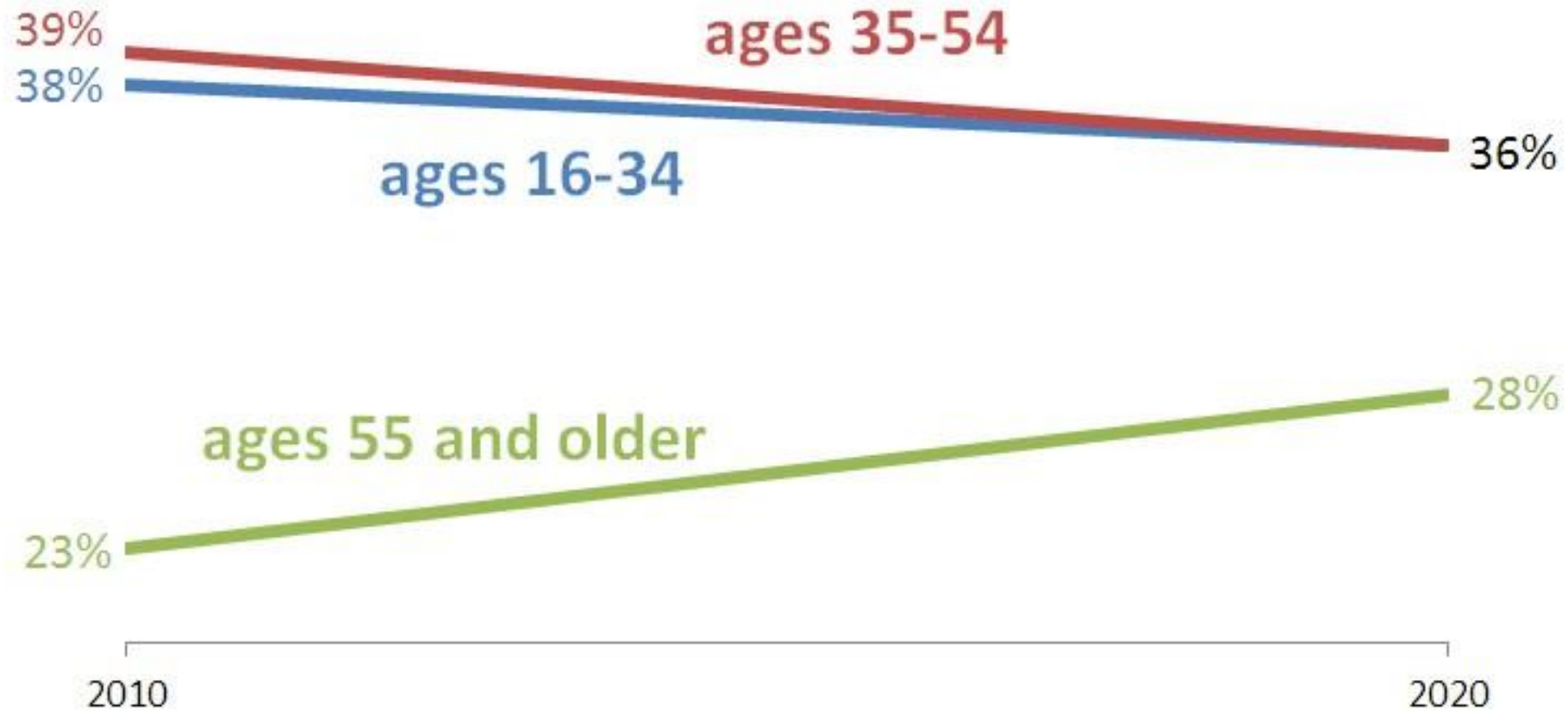
- US Census 2012: Of the 284 million US population age 5 and over: 24% speak another language at home
- By 2045 US population expected to reach “majority-minority”
- Under 18 age group will be there by 2018-19

# Age of DSPs in US



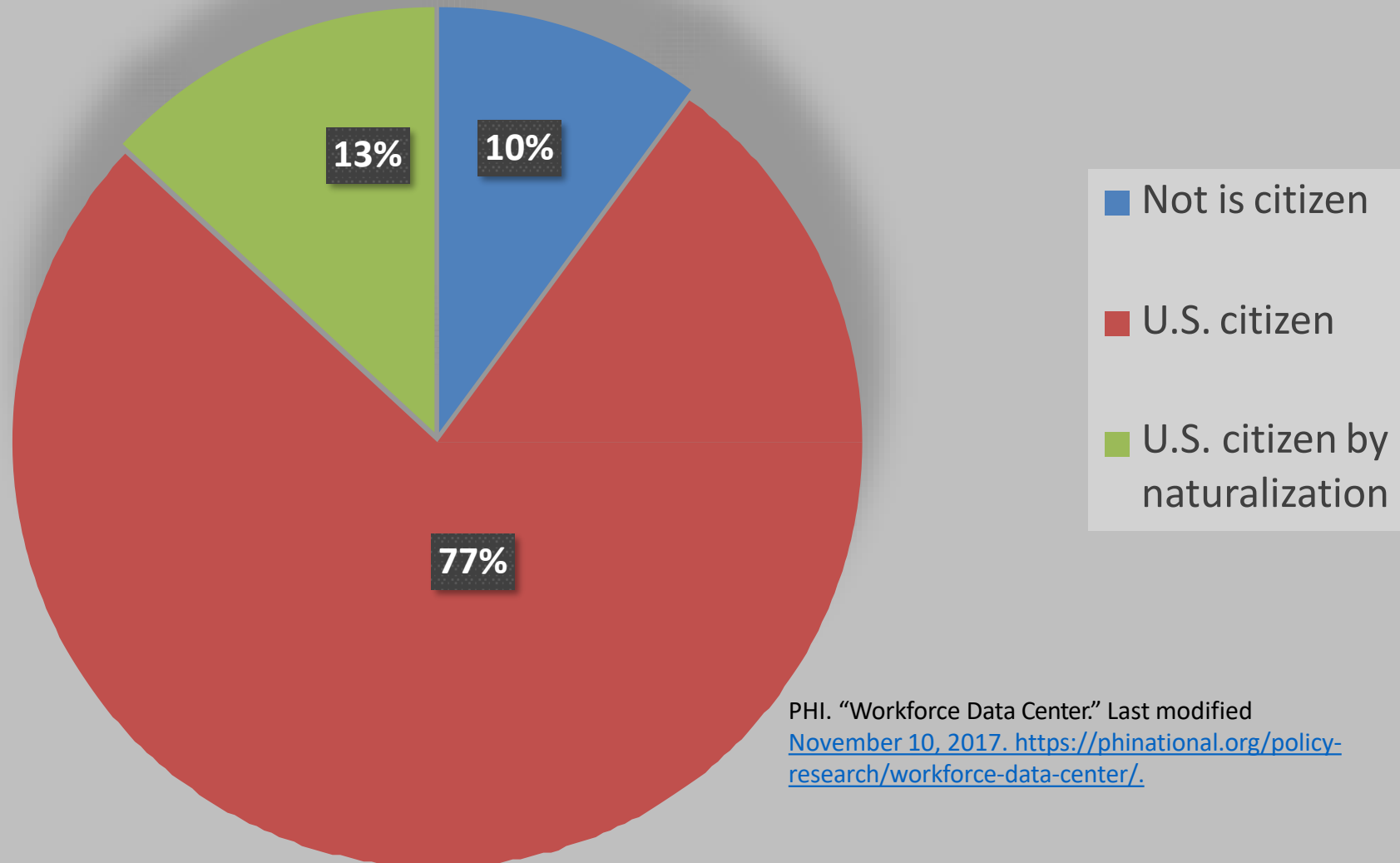
# Projected Aging of the Direct-Care Workforce, 2010-2020

U.S.





# DSP Citizenship Status in US



PHI. "Workforce Data Center." Last modified November 10, 2017. <https://phinational.org/policy-research/workforce-data-center/>.

# SNAPSHOT OF DIRECT SUPPORT WORKFORCE CHALLENGES IN THE UNITED STATES (NCI, 2018)

**NUMBER/STATUS  
OF DSPs**

Of the **224,818** DSPs employed in the 2,364 reporting organizations:



There was variance by state ranging from 23% - 74% of the DSP workforce being part-time.

**TURNOVER**



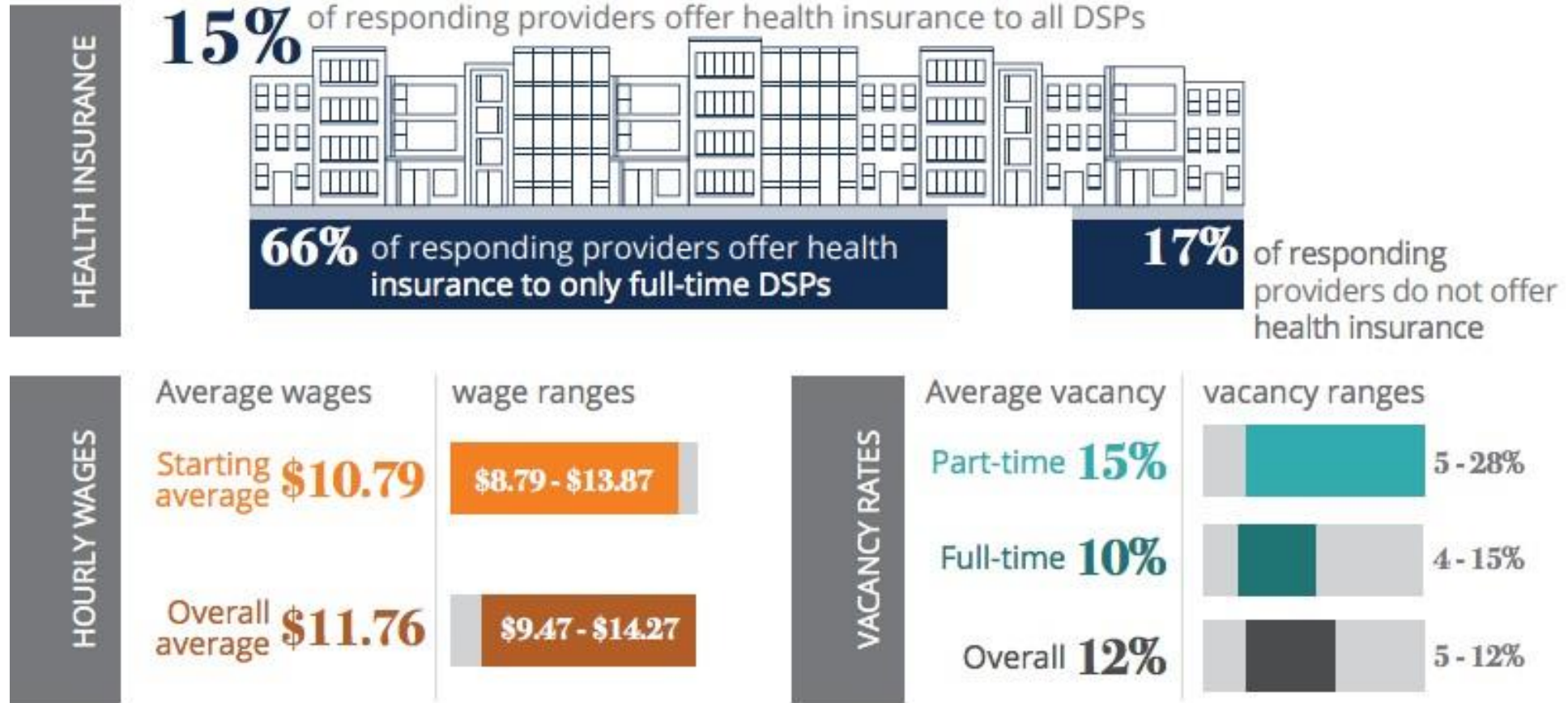
Of DSPs who left positions in calendar year 2016:



**TENURE**



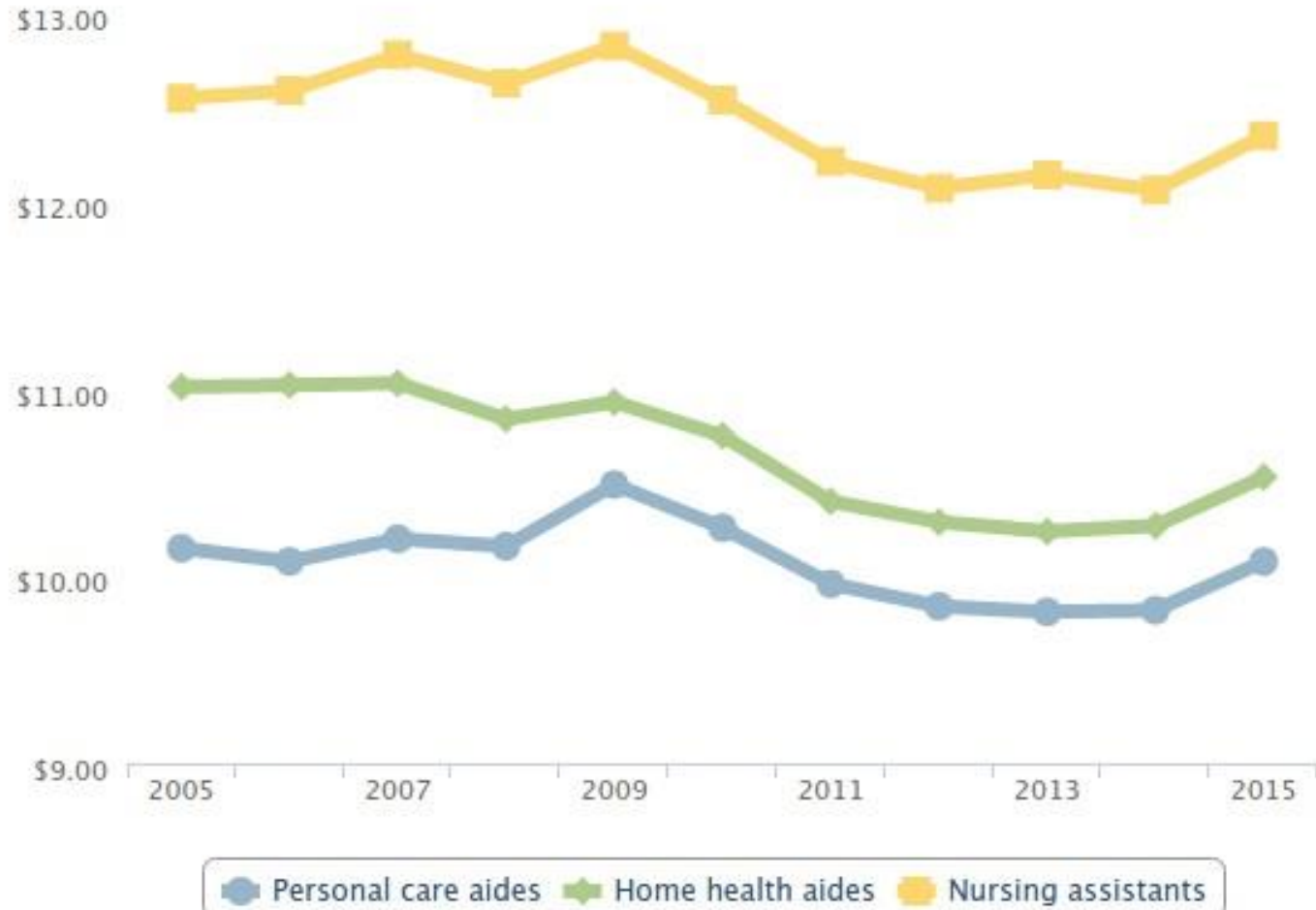
# Direct Support Workforce Challenges in the US, cont.



States: AL, AZ, CT, DC, GA, HI, IL, IN, MD, MO, NE, NY, OH, OR, PA, SC, SD, TN, TX, UT, VT

# United States: Median Hourly Wages for Direct-Care Workers, 2005 - 2015

Adjusted for Inflation (2015 dollars)



Source: PHInational.org

# Managed Long Term Services and Supports (MLTSS)

- Motivation: Unsustainable Medicaid spending
- State budget deficits, significant waiting lists
- Flexibility to deliver innovative solutions
- Contract and rate-setting transparency imperative
- Requires collaborative partnerships
  - People with disabilities, families, State, community based organizations, and payers
- Create network and provider capacity to support choice, self-determination, outcomes
- Working in some states (AZ, MI, WI, TN) – A real mess in others (KS, IA) – Jury's out (NY, TX, NC)

# Technology

- Remote monitoring
- Electronic Health Records
- Online learning
- Assistive tech
  - Increase independence
  - Connects people
  - Improves health outcomes











# HCBS Settings Rule

## Quick Summary

- Rule Finalized January 2014, effective March 2017
- States began submitting statewide transition plans in 2014
- **The Trump Administration delayed implementation 3 years to 2022**
- Pushback is mostly from presumed isolating settings or facility based settings – Trump Administration has shared they want to avoid unintended consequences but support the rule
- HHS/CMS has shared they are relooking at the HCBS Rule

# Electronic Visit Verification (EVV)

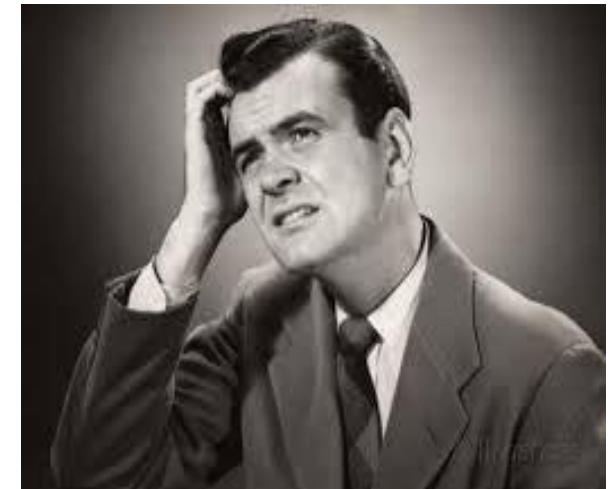


## History of EVV Legislation

- Initiated by 21<sup>st</sup> Century Cures Act passed Dec 2016
- Imposes penalty in the form of FMAP reduction for states not implementing EVV by certain dates
- Personal Care Services - .25% in 2019 → 1% after 2023
- Home Health Services - .25% in 2023 → 1% after 2027
- CMS guidance was published in May 2018
  - Legislative intent suggests I/DD services and non home-based services should be exempt; however, CMS has not clarified

# EVV Definitions

- From the legislation: The term ***personal care services*** means personal care services provided under a State plan under this title (or under a waiver of the plan), including services provided under sections 1905(a)(24), **1915(c)**, **1915(i)**, **1915(j)**, or **1915(k)** or under a waiver under section 1115
- FAQ Information
  - MCO Services? YES
  - PACE programs? NO
  - ICF/Nursing Facilities? NO
  - Group Homes? NO
  - Other Congregate Residential? NO
  - **Everything else? MAYBE**
  - Note: Changing title of personal care services...





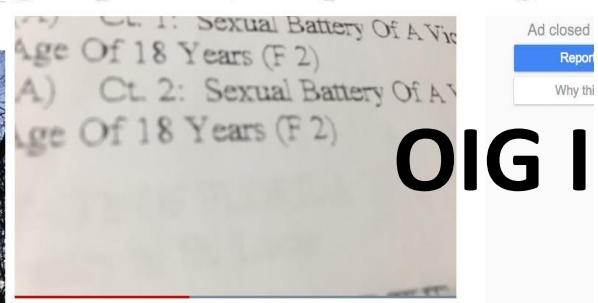
MINNEAPOLIS  
**In Minneapolis, a 'house of horrors' hidden in plain sight**  
Girls endured years of abuse, neglect; system did little

By Chris Serres Star Tribune | MARCH 12, 2018 — 11:15AM



UNSHOVED SIDEWALKS IN FRONT OF THE HOUSE WHERE JERRY LEE CURRY ALLEGEDLY ABUSED HIS TWIN DAUGHTERS UNTIL AUTHORITIES REMOVED THE YOUNG WOMEN FROM THE HOME LAST MAY.

f t e  
**Children with disabilities abused in group home, complaints allege**



A state-funded group home that is supposed to help South Florida children with disabilities has racked up a history of complaints including child abuse and neglect, police and state records show.

By Ryan Van Velzer - Contact Reporter

# OIG Investigations

<http://www.chicagotribune.com/news/watchdog/grouphomes/>

[OIG Report on Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight](#)

[Modifications to Quality Measures and Reporting in §1915\(c\) Home and Community-Based Waivers](#)

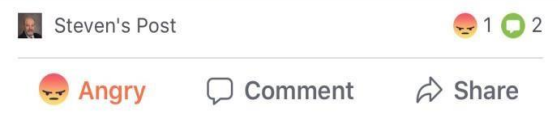
[Health and Welfare of Home and Community Based Services \(HCBS\) Waiver Recipients](#)



STATE

## Beset by rapes, rats, scalding, Florida home for disabled could lose license

BY CAROL MARBIN MILLER AND MONIQUE O. MADAN



Chicago Tribune News / Investigations  
ing in Secret



WNYS news Published by WNYC News  
**What Are Group Homes Hiding from Public? In One Case, Maggots.**



Aug 10, 2017 - by David Klepper  
From AP

## Other Important Disability Issues

- Legislation to limit coverage for pre-existing conditions
- Money Follows the Person (MFP) – legislation (Empower Care Act) is likely to move after the election to extend for at least one year
- Workforce Innovation and Opportunity Act (WIOA) Regulations – watch for possible changes here:

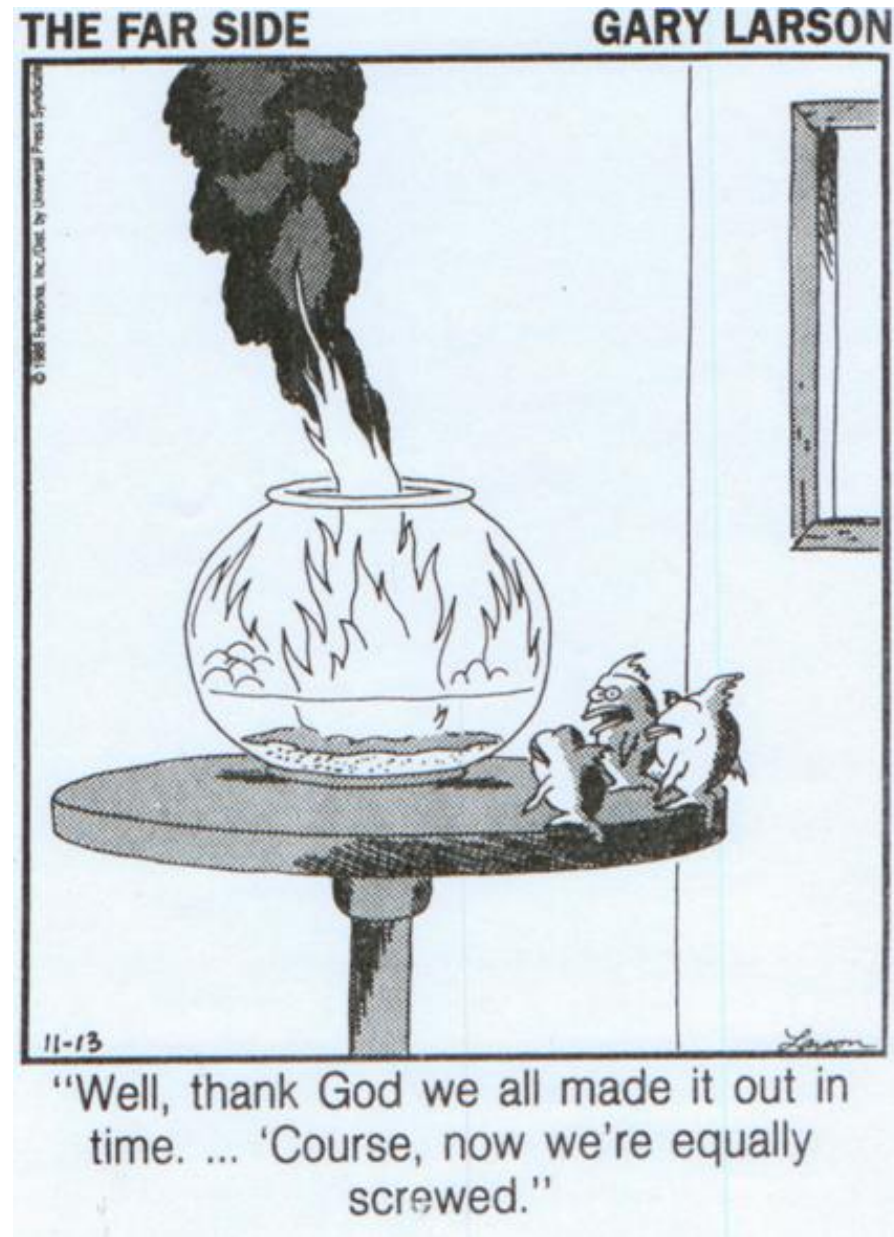
<https://www.reginfo.gov/public/do/eAgendaViewRule?pubId=201810&RIN=1820-AB79>

- Review of Overtime Rule – watch for changes here:

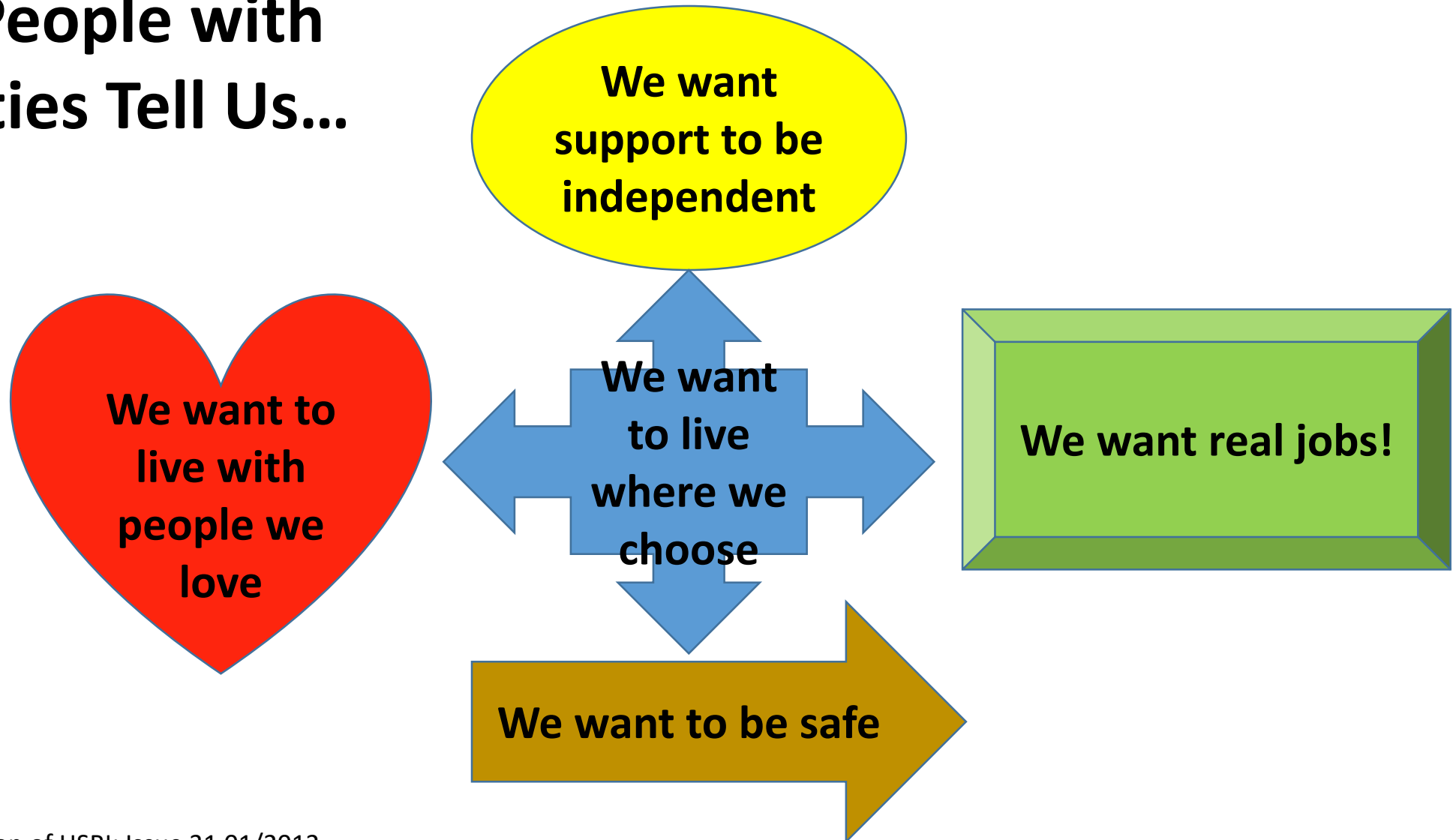
<https://www.reginfo.gov/public/do/eAgendaViewRule?pubId=201810&RIN=1235-AA20>



# Plan Ahead for Future Implications



# What People with Disabilities Tell Us...





## Community Integration

“Kenny, I’m Batman for Halloween. Will you be my Batmobile?”



# Questions



Diane McComb works with Qlarant providing technical expertise on disabilities, self-direction, individual budgets, community waiver programs, person centered practices, and managed care.

Prior to her current work she served as ANCOR's Liaison to State Associations, as the Deputy Secretary of the Maryland Department of Disabilities and the CEO of Maryland's state association of community programs. She also directed a community agency supporting people with intellectual and developmental disabilities and their families.

Her career gives her the unique perspective of a private community agency, the CEO of a statewide provider advocacy organization, and as a cabinet level governmental official. She brings her extensive knowledge of the disability community, her demonstrated track record of innovative problem solving, and lifelong commitment to creating improved capacity in systems empowering individuals with disabilities to achieve their personal and professional goals in communities where they live.

She holds an MEd from the Johns Hopkins University in Severe and Profound Disabilities and has a long history working as an advocate for people with disabilities and nonprofit management.

#### About the Presenter



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