

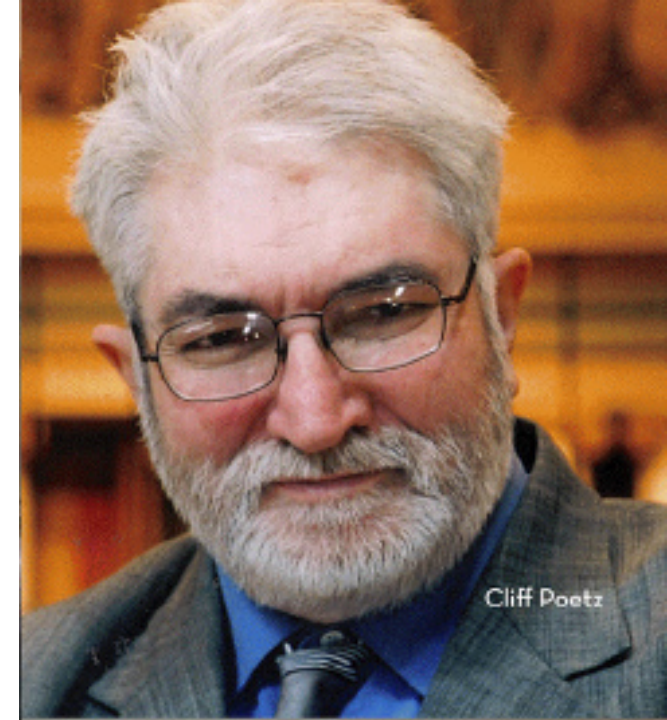


# Deinstitutionalization: Are we almost done or have we only just begun?

November 18, 2019  
AUCD



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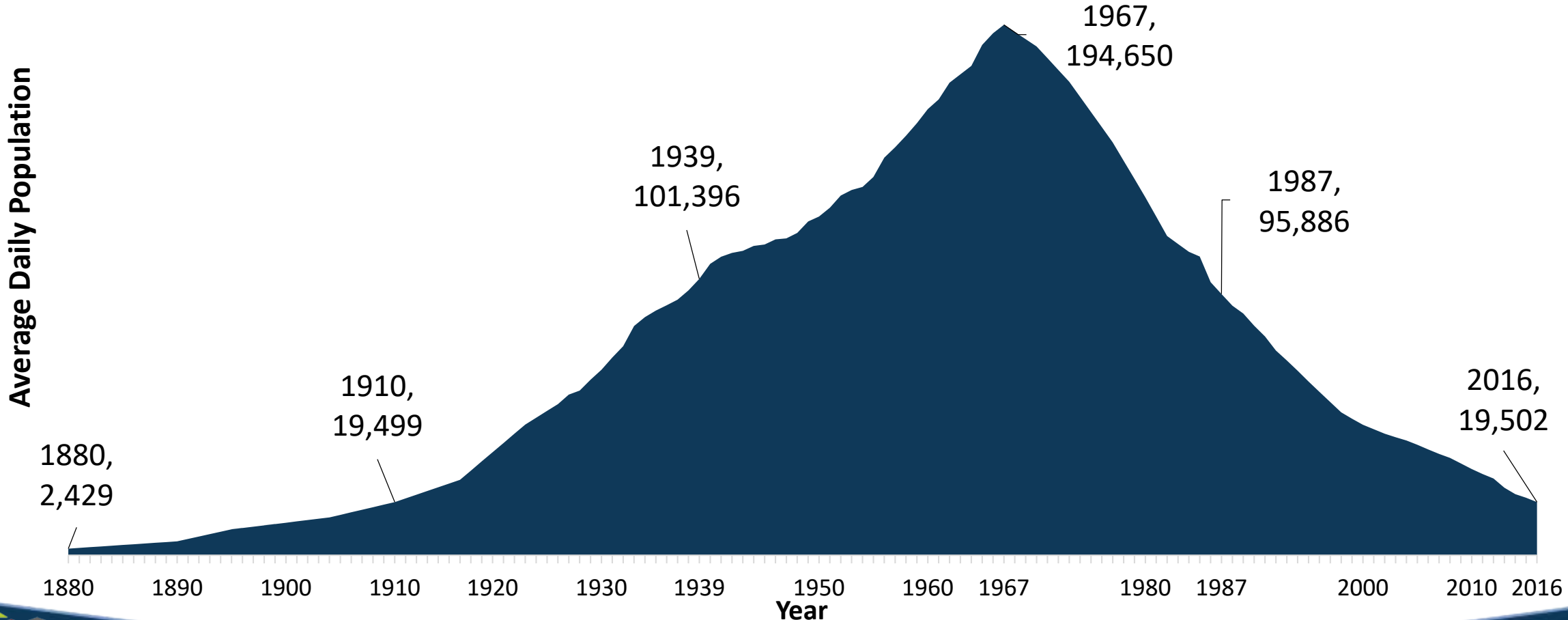


I AM DRIVEN TO  
MAKE HOME OWNERSHIP A  
REALITY FOR PEOPLE WITH  
DISABILITIES

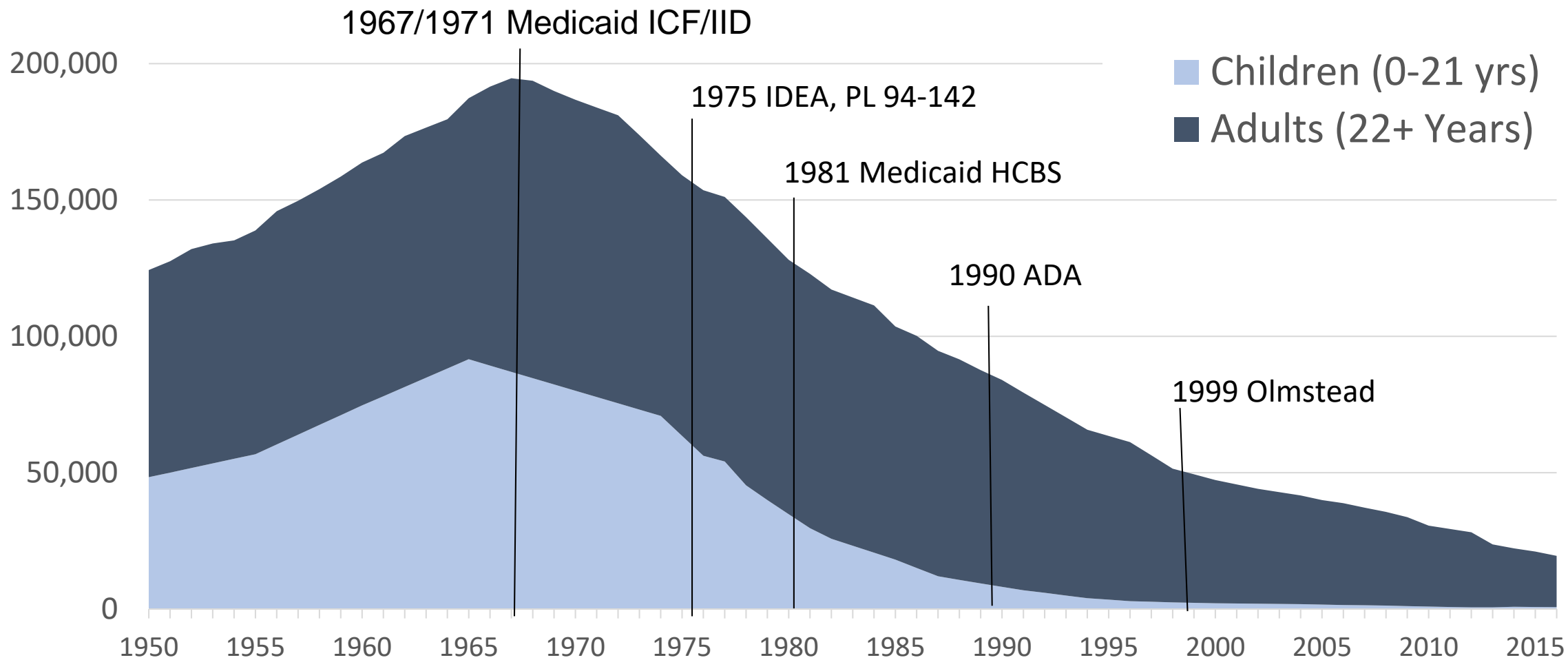


# Deinstitutionalization: Are we done?

# People in IDD Institutions 1880 to 2016

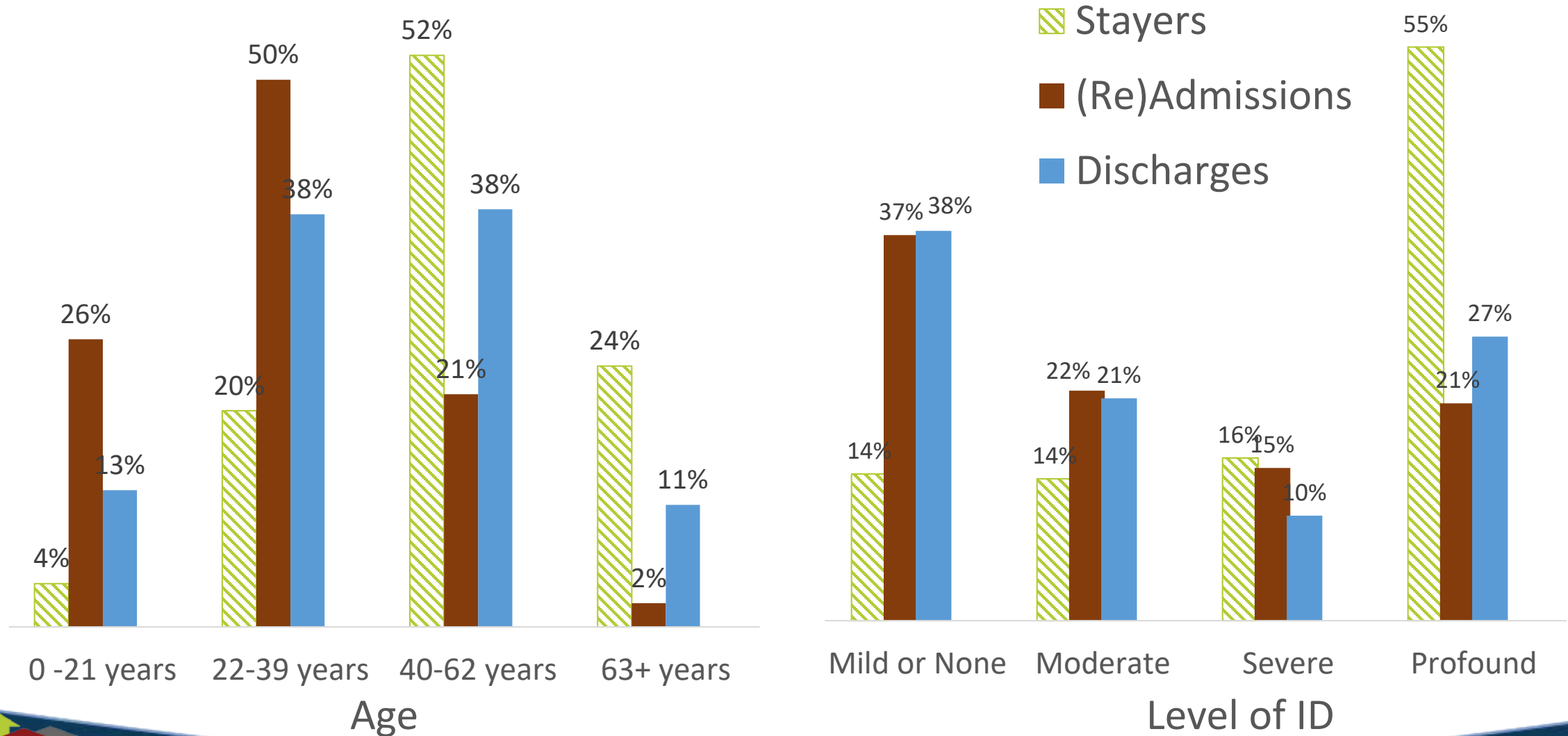


# Policy changes reduce number of children in institutions

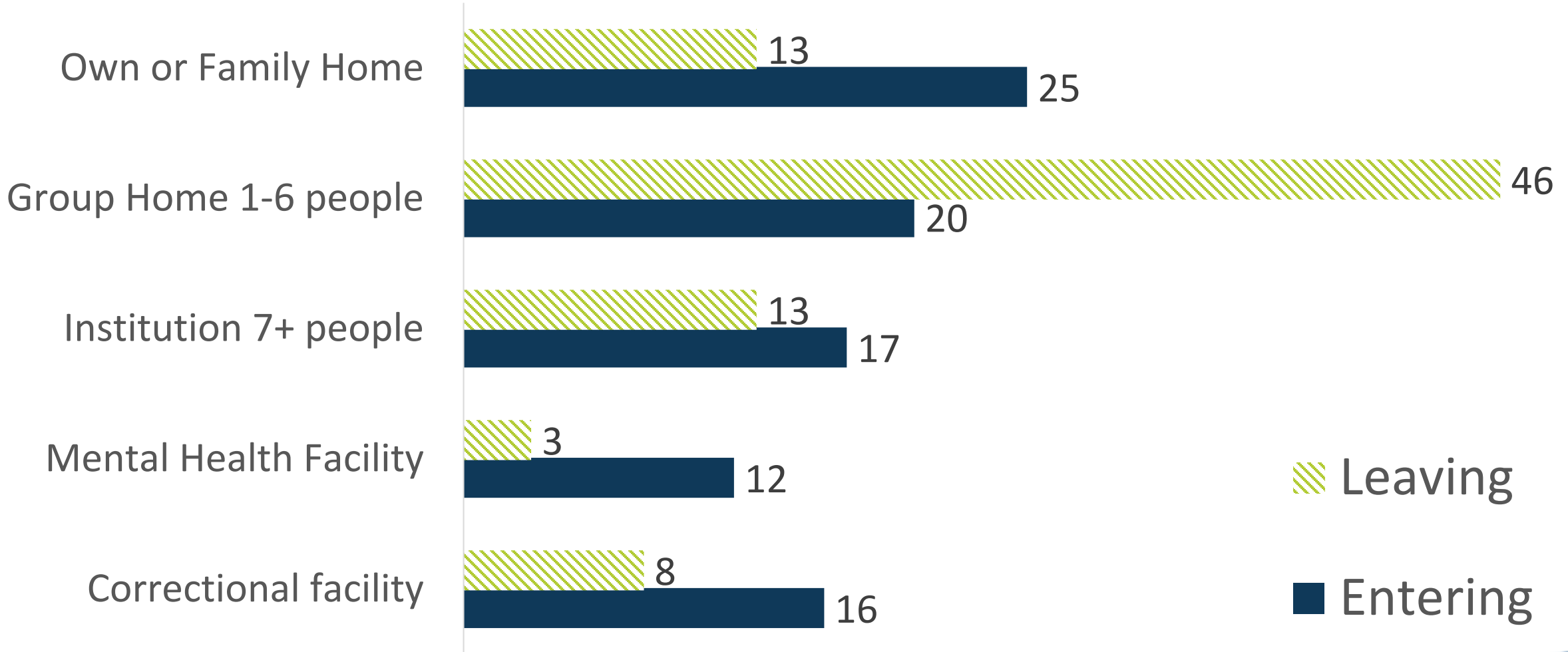


Source: RISP - Larson et al, 2018

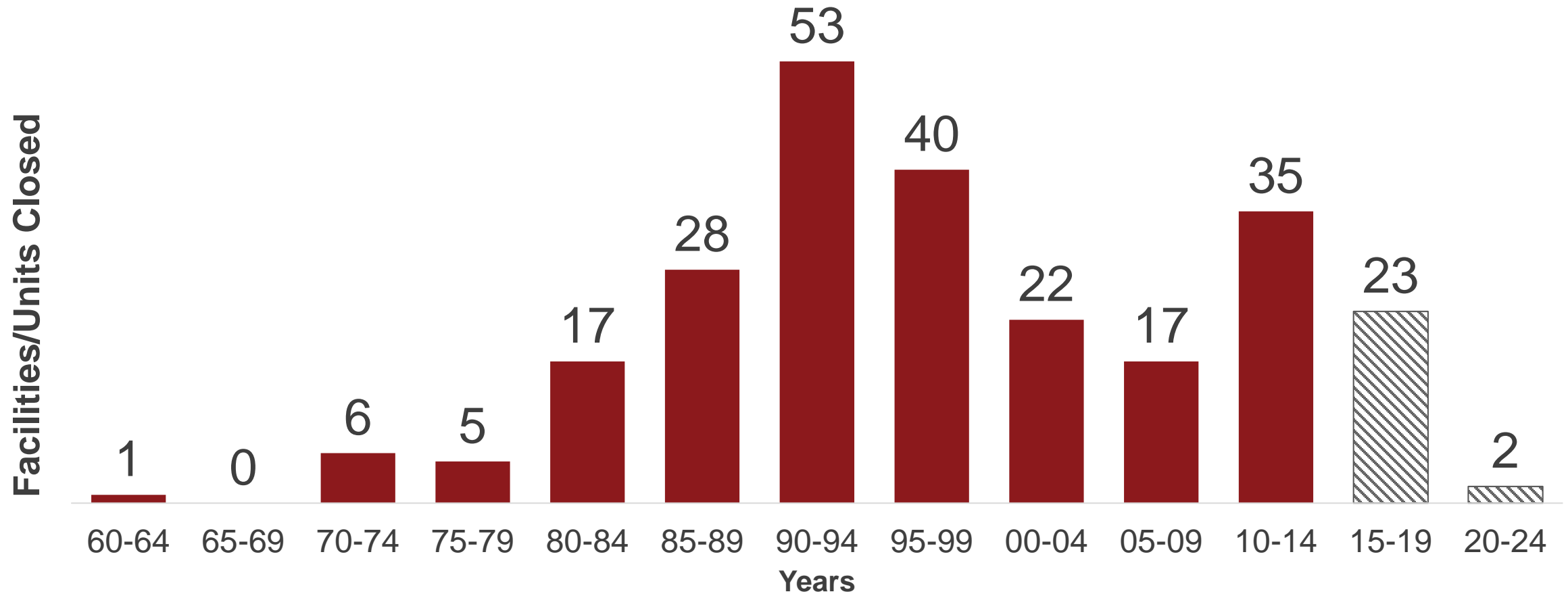
# Age and Level of IDD for People Entering and Leaving IDD Institutions



# Residence of People Entering/Leaving IDD Institutions



# IDD Institution Closures 1960 to 2024



Source: RISP - Larson et al, 2018









# IDD Residence Size 1977 to 2016

8% in settings of 16 people or more

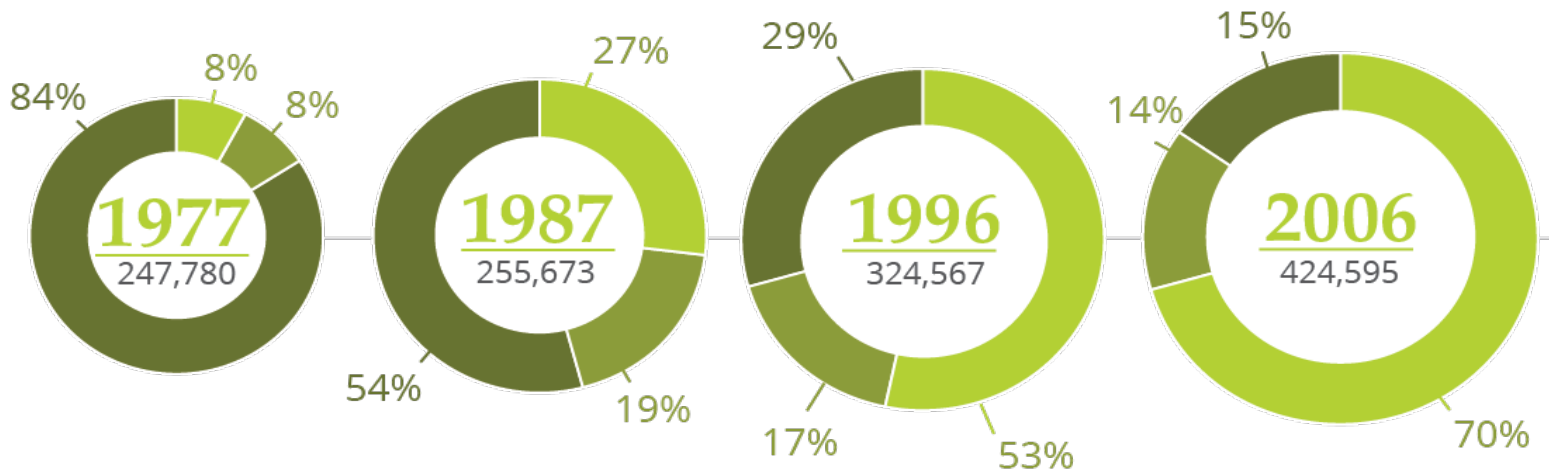
8% in settings of 7-15 people

84% in settings of 1-6 people

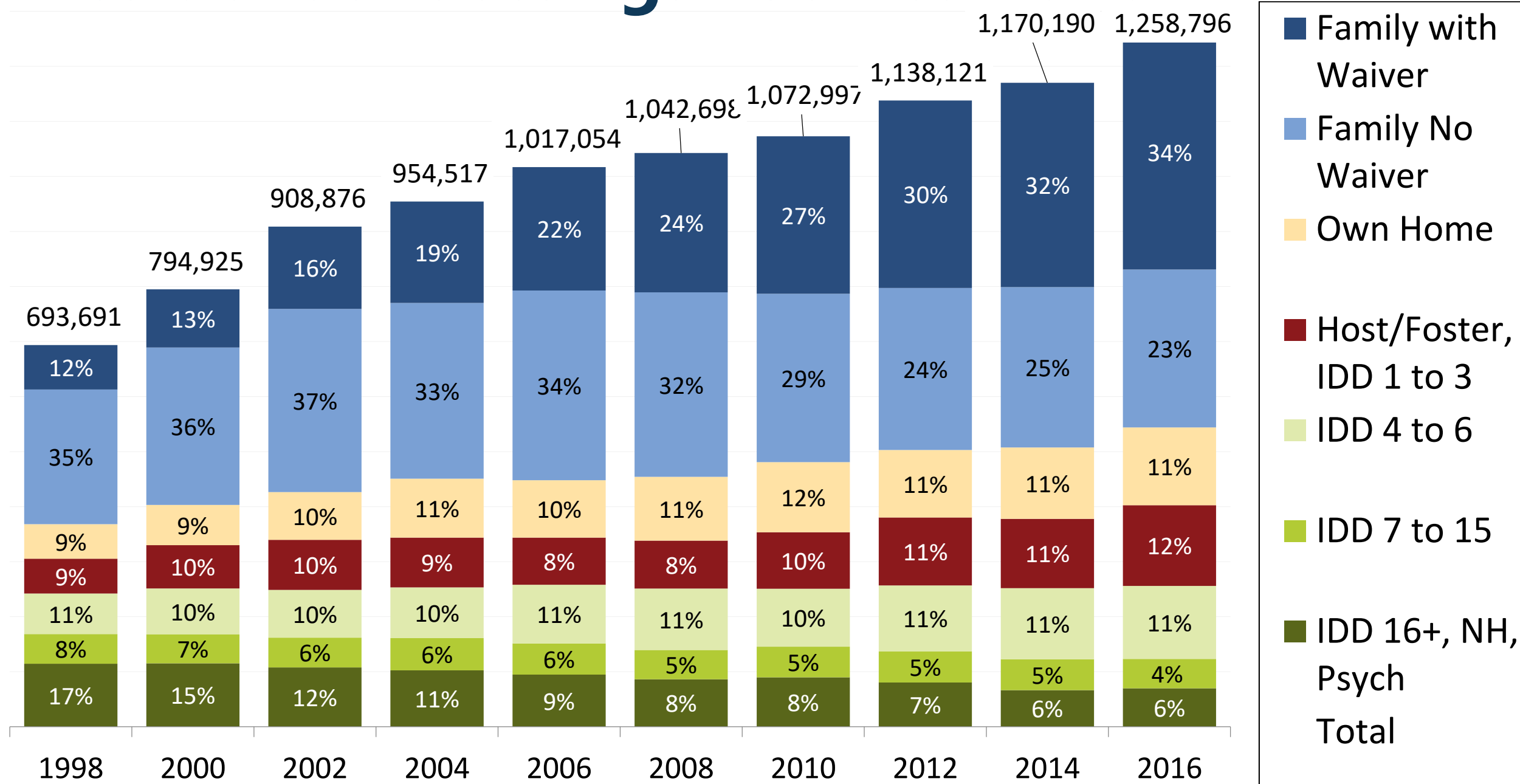


**year**

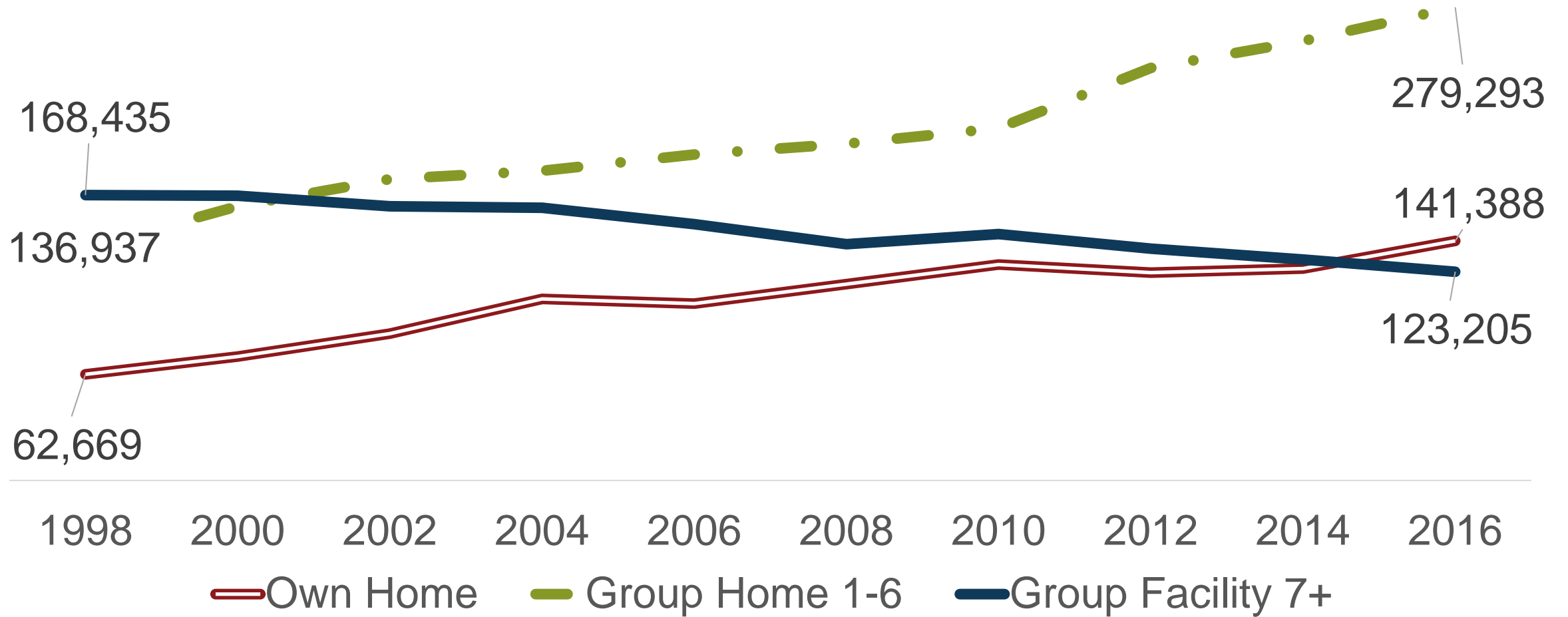
Number of people with IDD not living with a family member



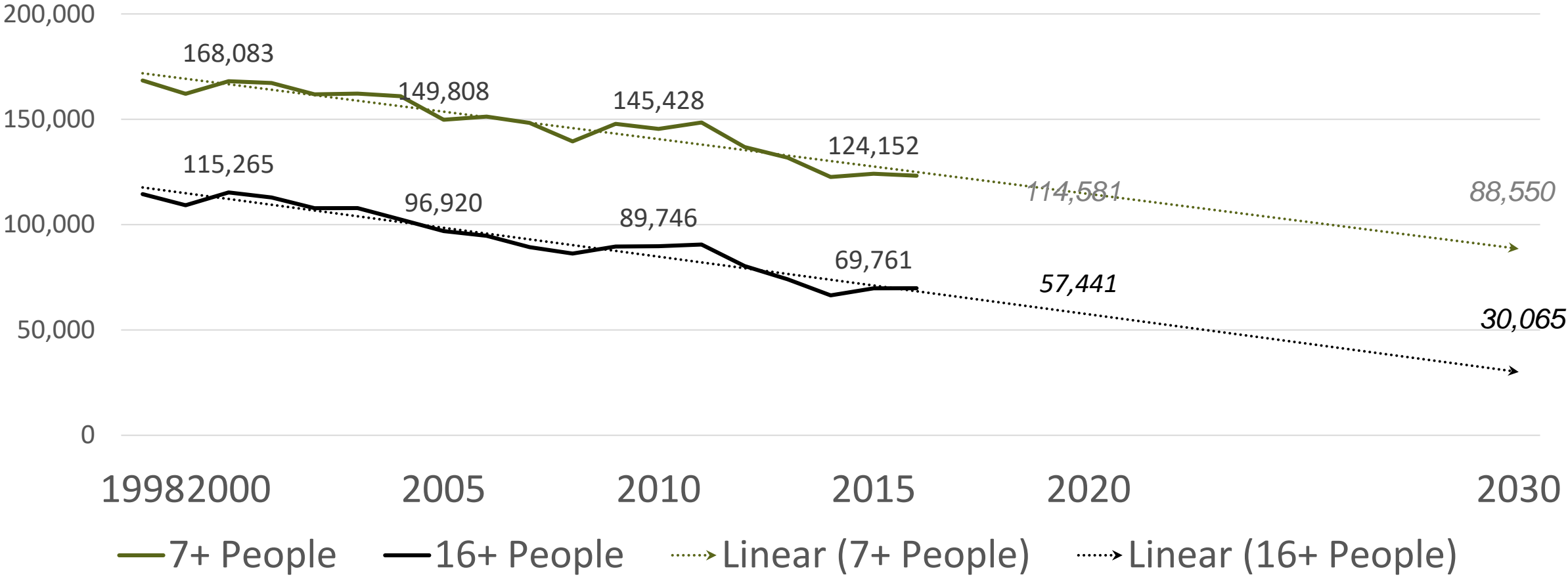
# Residential Settings 1998 to 2016



# More people now live in their own home or a small group home than in larger facilities



# People with IDD in congregate settings of 7 + people 1998-2016 with projections to 2030

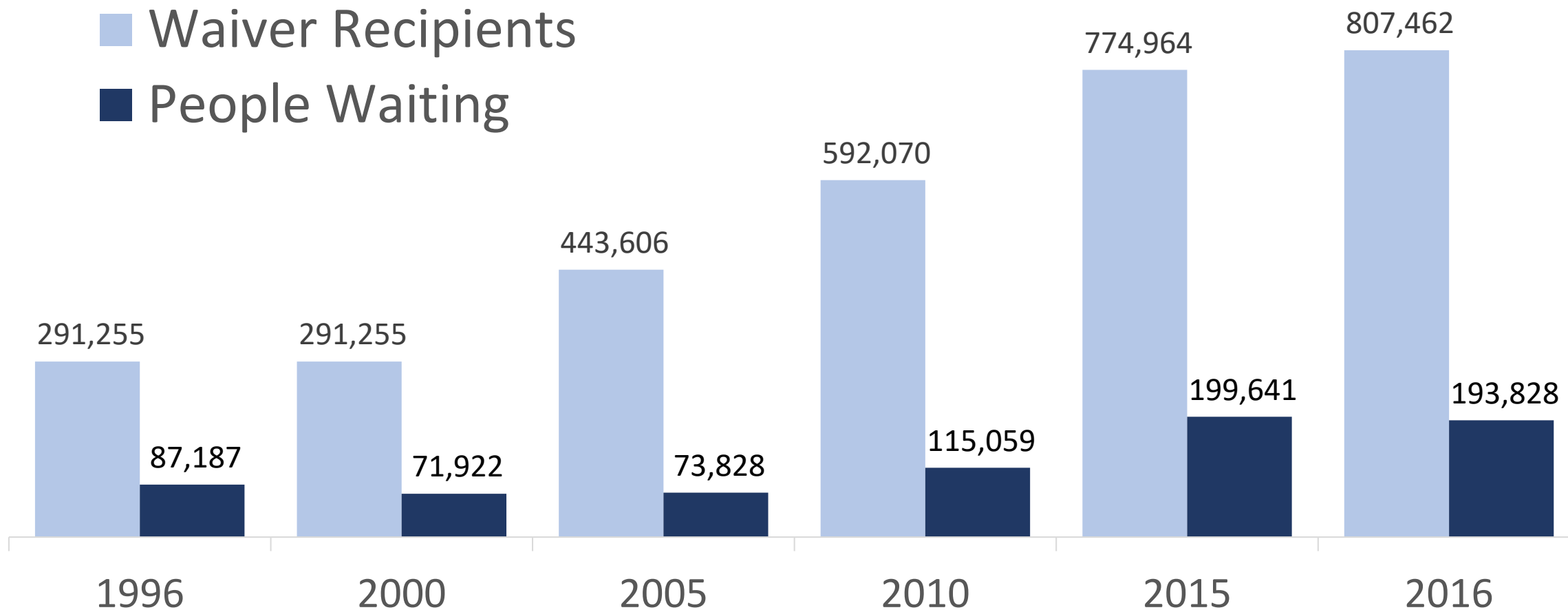


Includes ICF/IID, Nursing Homes and Psychiatric Facilities



**Or, Have We Only Just  
Begun?**

# Waiver Recipients vs People Waiting 1996 to 2016





# People with IDD in Today's Institutions

## ■ Child welfare

- 4,789 GH 7+ or institution

## ■ Special Education

- 7,155 Residential School
- 593 Correctional Facility

## ■ Jail/Prison

- 67,173 people with IDD (est.)

## ■ Nursing homes

- 26,381 with IDD (RISP)

## ■ Psychiatric facilities

- 3,715 people with IDD (RISP)

## ■ ICF/IID

- 74,615 people



# Normalization

People regardless of type or severity of disability should

- Be supported to live, play, work and learn in culturally normative and physically and socially inclusive settings
- Be treated with respect and dignity with right to make both big and little choices
- Be full participants in individualized daily routine
- Typical patterns of life (holidays, vacation, go places)
- Inclusive activities and settings typical for age

# 2014 Final HCBS Waiver Rules

Homes must

- Be integrated in and support full access to the community
- Be selected by the individual from among setting options
- Ensure individual rights of privacy, dignity and respect, and freedom from coercion and restraint
- Optimize autonomy and independence in making life choices
- Facilitate choice regarding services and who provides them

# Provider Owned Settings

- The individual has
  - a lease or other legally enforceable agreement
  - privacy in their unit including lockable doors,
  - choice of roommates and
  - freedom to furnish or decorate the unit;
- The individual controls his/her own schedule including access to food at any time;
- The individual can have visitors at any time; and
- The setting is physically accessible.



# Housing Models: New words or new ways

## ■ Intentional Communities

- Assisted Living
- Supported Living
- Independent Living
- Life care

## ■ Shared Equity

- Condos
- Co-housing
- Homeowner associations

## ■ Gated communities

## ■ Cluster housing

## ■ Vocational training facilities - Job corps

## ■ Post-secondary education or life skills training

# Challenges

- Waiting lists for publicly funded home and community based services
- Affordable accessible inclusive housing
- Available, accessible, affordable transportation
- Poverty, unemployment, under-employment
- The IDEA generation – expectations and experiences
- Dramatic increases in life expectancy

# Strategies

- Home ownership
- Integrated housing
- Universal Design and visit-ability standards
- Alternative financing: grants, lease to own, Able accounts, rent assistance
- Consumer controlled budgeting
- Housing-first approaches
- Separate housing from supports – If it doesn't work, the service not the resident leaves
- Accessible affordable public housing
- Enforcement of fair housing regulations

**Not finished yet**



# Residential Information Systems Project

<https://risp.umn.edu/>

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